B R I E F

Subject: Mobilizing the Office for Civil Rights' Authority to Address Obstetric Violence and Obstetric Racism
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Introduction

Pregnant people are more likely to die in childbirth today than was true a generation ago.[1] This is particularly concerning given the recent Supreme Court decision overturning *Roe* that will mean more people are forced to carry pregnancies to term. Despite growing national attention on racist perinatal health disparities in the United States, little scholarship has addressed the specific ways in which mistreatment throughout the perinatal period constitutes unlawful discrimination under our nation's major nondiscrimination protections. Pregnant people hold a myriad of identities that are both 1) at the root of much of the discrimination that they experience throughout pregnancy and childbirth and 2) protected traits under current U.S. civil rights law. However, discrimination during pregnancy has been woefully under-addressed in legal scholarship, likely due to the fact that the law thus far fails to recognize pregnancy as a protected characteristic,[2] and because discrimination during pregnancy has been so culturally entrenched.[3]

Being in the perinatal period exposes people to discrimination. We use the term "perinatal period" because discrimination may manifest throughout pregnancy, and after birth as a result of the pregnancy, regardless of the outcome of the pregnancy (miscarriage, abortion, early, late or term stillbirth, early, late or term live birth, infant and maternal morbidity or mortality). The overturning of *Roe* underscores the extent to which discrimination during pregnancy remains deeply entrenched both in our culture, and our laws. There is urgent need for action to address this and protect people in the perinatal period. Due to the relative inattention paid to pregnancies intended to go to term in contrast to those that end through abortion, we focus here on how discrimination manifests in childbirth, but indeed these issues are interconnected and warrant a coordinated response. This analysis compliments other work focusing on abortion and offers a more complete picture of exposure to discrimination in the perinatal period.

This document locates accountability for such discrimination within the existing non-discrimination legal frameworks that the Department of Health and Human Services' Office for Civil Rights (OCR) enforces. In Part One, it will define the nature and prevalence of obstetric racism and obstetric violence before explaining why OCR has authority to address it. This

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[1] Emily Petersen, et al., *Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017*, 68 Morbidity and Mortality Weekly Report 423, 423-429 (2019).

[2] In fact, a line of cases beginning with *Geduldig* established courts' refusal to classify pregnancy-based discrimination as sex discrimination to such an extent that Congress was moved to pass the Pregnancy Discrimination Act of 1978 to remedy employers' exclusion of pregnancy from employee health care plans. *See* Geduldig v. Aiello, 147 U.S. 484 (1974); Pregnancy Discrimination Act of 1978, Pub. L. No. 95-555, 92 Stat. 2076 (codified at 42 U.S.C. § 2000e-(k). In lieu of all that has been learned and exposed over the last 50 years, this inadequate legal posture clearly needs to be addressed.

[3] The United Nations recognized in a 2019 report that "violence against women in childbirth is so normalized that it is not (yet) considered violence against women." *See* United Nations Commission on Human Rights (UNCHR), Report by Special Rapporteur Dubravka Šimonović. *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, UN Doc A/74/137 (July 11, 2019) [hereinafter: "Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence."*].

section also points to parties who are responsible for and can be held accountable for perpetuating these forms of discrimination. Parts Two through Five will then analyze how each of the major nondiscrimination protections that OCR enforces apply in the perinatal period in the form of discrimination on the basis of race, sex, age and disability. Finally, Part Six will offer recommendations for ways in which OCR could address these forms of discrimination.

I. Obstetric Violence and Obstetric Racism are Widespread, and Forms of Discrimination that the Office for Civil Rights (OCR) Has the Authority to Address.

Respectful care is now a global priority and core component of many healthcare quality frameworks.[4] Global and local standards for perinatal services describe quality care as care that is trauma informed, anti-oppressive, and ensures an unconditional positive regard throughout healthcare interactions, and prioritizes informed decision-making and human rights.[5] These frameworks recognize that facilities, providers and health systems can and should be held accountable by States for these standards.[6] Yet Black, Indigenous, and other racialized and marginalized groups are less likely to receive the health services they need,[7] and they are two to three times more likely to report mistreatment during pregnancy and birth.[8] The health inequities that have persisted for decades, like maternal and infant mortality rates that are higher for Black and Indigenous families, are not just bad outcomes – they are symptoms of discrimination. The specific dimensions of both obstetric racism and obstetric violence discussed below signal the need for accountability. OCR is well-positioned to improve avenues for this accountability. The following section will provide a brief overview of 1) existing data surrounding the prevalence of obstetric racism and obstetric violence and 2) some of the ways in which OCR's enforcement mechanisms could be mobilized toward accountability for these harms.

A. Obstetric Violence and Obstetric Racism Happen, are Measurable, and Indicate the Need for Increased Protection and Enforcement of Civil Rights Laws in the Context of Perinatal Healthcare.

Pregnancy and childbirth are the most common reasons for accessing health care services, and significant disparities exist in outcomes and experiences among service users who

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[4] World Health Organization, *The Prevention and Elimination of Disrespect and Abuse During Facility-Based Childbirth* (2015); Olufemi Oladapo, et al., *WHO Better Outcomes in Labour Difficulty (BOLD) Project: Innovating to Improve Quality of Care Around the Time of Childbirth*, 12 Reprod. Health 1 (2015); World Health Organization, *WHO Recommendations: Intrapartum Care for a Positive Care Experience* (2018); Mary Renfrew et al., *Midwifery and Quality Care: Findings from a New Evidence- Informed Framework for Maternal and Newborn Care*, 384 THE LANCET 1129, 1129–45 (2014); Suellen Miller et al., *Beyond Too Little, Too Late and Too Much, Too Soon: A Pathway towards Evidence-Based, Respectful Maternity Care Worldwide*, 388 THE LANCET 2176, 2176–92 (2016).
[5] World Health Organization, *WHO Recommendations: Intrapartum Care for a Positive Care Experience* (2018).
[6] Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3.
[7] Emily Petersen, et al. *Racial/Ethnic Disparities in Pregnancy-Related Deaths – United States, 2007-2016*, 68 Morbidity and Mortality Weekly Report 762-765 (2019).
[8] *See* Samantha Artiga et al., *Racial Disparities in Maternal and Infant Health*, KAISER FAMILY FOUND. (Nov. 10, 2020), https://bit.ly/3aNqoLw.

are members of protected classes.[9] This section will discuss recent research that links these disparities to systemic racism and other forms of discrimination that manifest in a variety of ways, including (but not limited to) a lack of responsiveness, and dehumanizing behavior by health care providers.[10] It will then proceed to articulate and analyze common contexts in which this violence occurs.

1. Research Confirms that Mistreatment and Violence During Childbirth Are Prevalent and Widespread.

Representative surveys show strong evidence of discrimination, based on gender, race, body mass index, marital status, disability, and place of birth.[11] A majority of Black and Indigenous people report discrimination when accessing health care, including delays in receiving care that led to death and morbidity.[12] People with obesity, pregnancy complications, housing instability, poverty, substance use, or experiences with incarceration reported higher rates of mistreatment,[13] and these negative experiences are more common among people with intersecting identities and circumstances.[14] Facilities, health systems and providers have the ability to address these problems, and their failure to do so may be the result of unlawful discrimination.

Mistreatment is itself recognized as an adverse outcome as it constitutes a violation of basic human rights.[15] The language used to describe these harms has been developing with "respectful care" and "mistreatment" being used at the international level where "human rights" is the term for the mechanisms used to bring accountability for those harms.[16] "Obstetric violence" is also used internationally and is a term taken up first in the western hemisphere.[17] "Obstetric racism" first defined in the United States by Dr. Dána-Ain Davis,[18] describes the mechanisms and practices of subordination to which Black women and people's reproduction are

[9] World Health Organization, *The Prevention and Elimination of Disrespect and Abuse During Facility-Based Childbirth* (2015).
[10] *See e.g. Saraswathi Vedam, et al., The Giving Voices to Mothers Study: Inequity and Mistreatment During Pregnancy and Childbirth in the United States*, 16 Reprod. Health 77 (2019) [hereinafter Vedam et al., *Giving Voice to Mothers Study*].
[11] *See e.g.* Paige Nong et al., *Patient-Reported Experiences of Discrimination in the U.S. Health System*, 3 J. Am. Med. Ass'n Network Open e2029650 (Dec. 2020); Latoya Hill, Samantha Artiga & Sweta Haldar, *Key Facts on Health and Healthcare by Race and Ethnicity*, KAISER FAM. FOUND. (Jan. 26, 2022), https://bit.ly/3QpRjNY.
[12] Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10.
[13] *See e.g.* Gita Sen, Bhavya Reddy & Aditi Iyer, *Beyond Measurement: The Drivers of Disrespect and Abuse in Obstetric Care*, 26 Reprod. Health Matters 6 (2018) ("Poverty, fertility and gender can form a powerful axis for discrimination in maternal health service provision, which may be further layered with racial, ethnic, religious, caste or other biases. Prejudices against certain categories of women (multi-gravid or obese women, women with histories of repeated abortions or HIV) can seep into the fabric of healthcare organisations, making disrespectful interactions less of a random individual-centric act and more of an operational norm."); Rebecca Stone, *Pregnant Women and Substance Use: Fear, Stigma, and Barriers to Care* 3 Health Justice 2 (2015); Rachel Roth, *Incarceration as a Threat to Reproductive Justice in Massachusetts and the United States*, 39 W. New Eng. L. Rev. 381 (2017).
[14] *See id.*
[15] *See e.g.* Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10; Rajat Khosla, et al. *International Human Rights and the Mistreatment of Women During Childbirth*, 18 Health & Hum. Rights J. 131 (2016).
[16] *See* Kholsa et al., *International Human Rights and the Mistreatment of Women During Childbirth*, *supra* note 15.
[17] Caitlin Williams, et al. *Obstetric Violence: A Latin American Legal Response to Mistreatment During Childbirth*, 125 Brit. J. Obstetrics & Gynaecology 1208 (2018).
[18] Dána-Ain Davis, *Obstetric Racism: The Racial Politics of Pregnancy, Labor and Birthing*, 38 Med. Anthropology 560 (2018) [hereinafter "Davis, *Obstetric Racism"*].

subjected that track along histories of anti-Black racism. According to Davis, "obstetric racism" transcends the limits of "obstetric violence" and "medical racism" and locates the specific ways that the reproducing Black body is subjected to medical encounters, experimentation, exploitation, and extraction based on racial hierarchies dating back to slavery, which structure Black value as it is constituted in the engagements of Black women, transgender and gender diverse (TGD) people within the biomedical and healthcare infrastructures.[19]

A taxonomy of harms has been developed by researchers with some versions including a dozen types. In this memo we use the terms "obstetric racism" and "obstetric violence" because these terms identify the context of the harms (obstetrics) and its most virulent forms (racism and violence). Obstetric racism and obstetric violence are similar yet different forms of discrimination that often involve a combination of sexism, racism and other forms of discrimination rooted in stereotypes and norms that situate white, able-bodied, cis-gendered, heterosexual people at the center and as the ideal to be reproduced. The following sections will articulate some of the common contexts in which this violence occurs.

2. Conflicts Between Providers and Patients Are a Common Source of Obstetric Violence and Obstetric Racism.

Often, obstetric violence or obstetric racism occurs when, or because, a pregnant person exercises their right to refuse medical care.[20] In the Changing Childbirth in British Columbia (CCinBC) mixed-methods study, researchers conducted a content analysis of 1,540 written accounts from more than 1,123 women who reported on procedures they declined, why they declined the procedures, and the results of those decisions.[21] Niles and colleagues described the impact on service users along four themes: 1) contentious interactions—combative relationships with providers emerge when they decline care; 2) knowledge as control and power; 3) morbid threats—providers make extreme threats when pregnant people decline interventions; and 4) compliance as valued—social cues that people were perceived as a "good client" if they suppressed questions or a desire to decline care.[22] The doctrine of informed consent[23] supports the right to refuse, and should reinforce the ability of health systems, facilities, and providers to follow the law, but it has proven to be inadequate. This further underscores the nature of the problem as discrimination.

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[19] Dána-Ain Davis, *Reproducing While Black: The Crisis of Black Maternal Health, Obstetric Racism and Assisted Reproductive Technology*, 11 Reprod. Biomed. Soc. Online 56 (2020) [hereinafter "Davis, *Reproducing While Black"*].

[20] Rachel Jewkes, Naeemah Abrahams, & Zodumo Mvo, *Why Do Nurses Abuse Patients? Reflections from South African Obstetric Services*, 47 Soc. Sci. & Med. 1781 (1998).

[21] Birth Place Lab, *Changing Childbirth in British Columbia: Report* (2019), https://bit.ly/3QmpF4s.

[22] *Id.*

[23] Informed consent is both an ethical and legal obligation of medical providers in the US and refers to "the process in which a health care provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention." The process of informed consent occurs when communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention. The process requires both information and consent or refusal. *See* Parth Shah, et al., *Informed Consent*, StatPearls (Jun. 14, 2021); *See also* American Medical Association, *Code of Medical Ethics Opinion 2.1.1: Informed Consent* (accessed June 24, 2022), https://bit.ly/2XGIMhR; American College of Obstetricians & Gynecologists, *Informed Consent and Shared Decision Making; Ethics Committee Opinion No. 819*, 137 Obstetrics & Gynecology e34 (2021); American College of Obstetricians & Gynecologists, *Informed Consent: Ethics Committee Opinion No. 439*, 114 Obstetrics & Gynecology 401 (2009).

All pregnant people are not equally subjected to punishment or mistreatment as a result of their refusal of medical care. Logan et al. explored consent, coercion and violations of consent in the *Giving Voice to Mothers* study and found that Black and racialized respondents in the US reported significantly more rights violations, and that certain intersecting factors play a role in the experience of mistreatment, (e.g. socioeconomic status, disability, body mass index, model of care, social & pregnancy risks).[24] Obstetric racism offers a nuanced multi-dimensional conceptual framework that is helpful in identifying some of the specific ways in which race-based discrimination underlies modern day clinical and research protocols, practices, procedures, programs, policies.[25] Dr. Davis has delineated six dimensions of obstetric racism. The six dimensions are diagnostic lapses; medical abuse; intentionally causing pain; coercion; neglect, dismissiveness or disrespect; and ceremonies of degradation.[26] These forms of obstetric racism will be elaborated upon further in Part II, but for now it is important to understand that discriminatory attitudes about race underly each of them and manifest in clinical and research protocols, practices, procedures, programs and policies over which health systems, facilities and providers have control.

Indeed, after controlling for these factors in the analysis, Logan et al. (2021) found that these inequities in treatment by providers can only be explained by how people are treated differently based on their racial identity – i.e. discrimination.[27] Both the Logan et al. and CCinBC studies highlight that patients experience pressure, coercion or manipulation to accept procedures from providers when they initially decline what has been presented by providers as an "offer" or choice in care options.[28]

Several researchers have examined patient-provider dynamics and power relationships when perinatal care decision-making occurs.[29] Patients and providers may have different values and priorities. Clinicians report the complexity of respecting a patient's choice when their desires are in conflict with the provider's understanding of evidence-based maternity care.[30] However, patient safety and quality literature consistently address how this gap in provider–patient relationships and communication impacts health outcomes. Indeed, OCR can help clarify for providers and facilities that clinical outcomes alone are not the only measure of quality or even

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[24] Rachel Logan et al., *Coercion and Non-Consent During Birth and Newborn Care in the United States*, BIRTH (April 2022), https://doi.org/10.1111/birt.12641.

[25] Karen Scott & Dána-Ain Davis, *Obstetric Racism: Naming and Identifying a Way Out of Black Women's Adverse Medical Experiences*, 123 Am. Anthropologist 681 (2021) [hereinafter Scott & Davis, *Obstetric Racism*]; Karen Scott, *The Rise of Black Feminist Intellectual Thought and Political Activism in Perinatal Quality Improvement: A Righteous Rage about Racism, Resistance, Resilience and Rigor*, 2 Feminist Anthropology 155 (May 2021); Saidiya Hartman, *The Belly of the World: A Note on Black Women's Labors*, 18 Souls 166 (June 2016).

[26] *See generally* Davis, *Reproducing While Black*, *supra* note 19.

[27] Logan et al., *Coercion and Non-Consent During Birth and Newborn Care in the United States*, *supra* note 24.

[28] *Id.; see also* Birth Place Lab, *Changing Childbirth in British Columbia: Report*, *supra* note 21.

[29] Sandra Healy, Eileen Humphreys & Catriona Kennedy, *Midwives' and Obstetricians' Perceptions of Risk and Its Impact on Clinical Practice and Decision-Making in Labour: An Integrative Review*, 29 Women Birth 107 (Sept. 2015); Cynthia Hunter et al., *Learning How We Learn: An Ethnographic Study In a Neonatal Intensive Care Unit*, 62 J. Advanced Nursing 657 (May 2008); Wendy Hall, Jocelyn Tomkinson & Michael Klein, *Canadian Care Providers' and Pregnant Women's Approaches to Managing Birth: Minimizing Risk While Maximizing Integrity*, 22 Qualitative Health Rsch. 575 (Apr. 2012); Monica McLemore et al., *Health Care Experiences of Pregnant, Birthing and Postnatal Women of Color at Risk for Preterm Birth*, 201 Soc. Sci. Med. 127 (Mar. 2018).

[30] *See e.g.* Kathie Records & Barbara L. Wilson, *Reflections on Meeting Women's Childbirth Expectations*, 40 J. of Obstetric, Gynecologic & Neonatal Nursing 394 (July 2011); Meike Müller-Engelmann, *Shared Decision-Making in Medicine: The Influence of Situational Treatment Factors*, 82 Patient Educ. & Counselling 240 (Feb. 2011).

adequacy, that there is no balancing test between health outcomes and civil rights, that upholding patient protections and rights are a required health outcome.

3. Use of Threats, Coercion and Force Are Common Forms of Obstetric Violence and Obstetric Racism.

In addition to the racial profiling and racialized neglect described above, discrimination on the basis of race, color, or national origin in the health care setting during the perinatal period presents as providers using threats, coercion, and force against birthing people of color when disagreements emerge.

Longstanding systemic inequities in care and a lack of racially-concordant providers, as well as patients' past experiences of racism within health systems undermine the trust required for the patient-provider relationship.[31] Furthermore, stereotypes about people of color may lead health care providers to perceive their patients as more "combative" or "difficult," or less able to make sound healthcare decisions for themselves.[32] The result is racialized conflict when providers seek to force pregnant patients – or induce their acquiescence by threats – to unwanted medical interventions, and this is racially discriminatory.[33] This racially-biased harm during the perinatal period gives rise to OCR enforcement authority as described in Section 1557, particularly when the provider abuses the law and legal processes to carry out the coercion.

Coercion is also frequently used against pregnant people with disabilities (who may also experience racialized conflict). For example, pregnant people with disabilities are routinely denied an equal opportunity to participate in decision-making surrounding their perinatal care. This inequity can manifest itself in a variety of different ways including (but not limited to) being denied complete information about one's options or being subjected to paternalistic attitudes about one's decision-making capacity as a pregnant person with disabilities.[34] Like racism, these harms stem from centering white, cisgender, able-bodied men and lead to the harmful and discriminatory belief that people with disabilities- whether physical, cognitive or intellectual- should not be sexually active or reproduce, and that they cannot make their own decisions about their bodies, and by extension, their healthcare.[35] These beliefs can lead to coerced interventions or procedures done without consent, including both sterilization and cesarean surgery.[36]

At the center of the threats, coercion, and force experienced by birthing people is a discriminatory perversion of the core legal principle that people have sovereignty over their own bodies. As the U.S. Supreme Court has observed, "[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and

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[31] Brad N. Greenwood, *Physician–Patient Racial Concordance and Disparities in Birthing Mortality for Newborns*, 117 Proceedings of the Nat'l Acad. Of Sci. of the Americas 21194 (Aug. 17, 2020).
[32] *See* Khiara Bridges, *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization* (Cal. Univ. Press, 2011).
[33] *See, e.g.*, Farah Diaz-Tello, *Invisible Wounds: Obstetric Violence in the United States*, 24 Reprod. Health Matters 56 (2016); Elizabeth Kukura, *Birth Conflicts: Leveraging State Power to Coerce Health Care Decision Making*, 47 U. Balt. Law Rev. 247 (2018); Nancy K. Rhoden, *The Judge in the Delivery Room*, 74 Cal. L. Rev. 1951 (1986); Davis, *Obstetric Racism*, *supra* note 18.
[34] Anita Silvers, Leslie Francis & Brittany Badesch, *Reproductive Rights and Access to Reproductive Services for Women with Disabilities*, 18 Am. Med. Ass'n J. of Ethics 430 (2016).
[35] *Id.*
[36] *Id.*

unquestionable authority of law."[37] The law generally expects facilities and individuals who provide public accommodations to honor this right.

More than a century of legal precedent dictates that every adult of sound mind has the right to be free from unwanted touching – even if for the purposes of medical treatment.[38] This principal has not been breached by overturning *Roe*. Freedom to make decisions about one's own body is encompassed by other constitutional protections.[39] Likewise, the state may not transgress this right except under very limited circumstances and upon showing of a compelling state interest that is actually advanced by the incursion into bodily autonomy, and that the incursion is no greater than necessary to effectuate that interest.[40]

Nevertheless, pregnant people, and especially pregnant people of color and pregnant people with disabilities, are vulnerable to incursions into their bodily autonomy. Even more so now. Pregnant people have already been reporting that health care providers employ a variety of threats, to induce compliance with medical advice. Threats occur within health facilities, supported by health facility policies, and enacted by health facility staff or providers who work at the facility, and include the threat to compel action through legal process such as court orders for unwanted procedures and reports to family regulation authorities. These entities have the power to follow through on these threats and often do. Because these threats are used to undermine the civil and decision-making rights of pregnant and laboring people, such threats as are a form of discrimination.

a) Interventions Compelled by Legal Process.

Interventions compelled by legal process are particularly effective and illustrate the connection between health systems, facilities, providers and the State. At worst, health systems, facilities and providers use the state to exert control over pregnant and postpartum people. This can include forcing psychological evaluations and medical interventions upon the parent or the newborn through court orders, regulating the family through reports, investigations, child removal and termination of parental rights through the family regulation system (also known as "child protective services" but we will use more accurate term "family regulation"[41]), and punishment and control through criminal charges.[42] When they use these tactics health systems, facilities and providers depart from their therapeutic and caretaking roles and enact discrimination.

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[37] Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891).
[38] Schloendorff v Socy. of New York Hosp., 211 N.Y. 125, 129 (1914).
[39] *See, e.g.*, Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring)("[T]he liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment. . . .").
[40] *See* Washington v. Glucksberg, 521 U.S. 702, 721 (1997). A notable exception is the decision, in *Buck v. Bell* which gives states the power to forcibly sterilize people based on eugenic principles which are now out of fashion.
[41] Dorothy Roberts, *The Regulation of Black Families*, REGULATORY REV. (Apr. 20, 2022), https://bit.ly/3F8e83m.
[42] *See* Lynn M. Paltrow & Jeanne Flavin, *Arrests of and Forced Interventions on Pregnant Women in the United States, 1973–2005: Implications for Women's Legal Status and Public Health*, 38 J. Health Politics, Pol. & L. 299, 326-27 (2013); Lisa Sangoi, *"Whatever they do, I'm her comfort, I'm her protector." How the Foster System Has Become Ground Zero for The U.S. Drug War*, MOVEMENT FOR FAMILY POWER (June 2020), https://bit.ly/3xtprQe [hereinafter "Sangoi, Ground Zero Report"].

These examples of obstetric racism and violence cloaked in state power are no less violent than the "obstetric slaps"[43] and symphysiotomies[44] endured by birthing people in other countries. It may involve unwanted intrusions like vaginal examinations, episiotomy (cutting the perineum), or even cesarean surgery. It may involve forcibly subduing a pregnant person in service of a medical intervention, such as in the case of a Nigerian woman in Illinois who was so distressed after being told she would be forced to have a court-ordered cesarean section that she physically resisted, only to be placed in leather restraints and bite through her intravenous line.[45] The interventions may be objectively unnecessary, as was the case with a Black mother in Georgia who was given a dire prognosis of near-certain death to her fetus and ordered to submit to surgery, only to have the condition resolve with delivery of a healthy baby.[46] Or the intervention may be futile, as was the case with the court-ordered bed rest and cesarean section forced upon a Florida woman that failed to prevent her pregnancy loss.[47]

As with most forms of invidious discrimination prohibited by law, the underlying racial bias is generally not documented by the perpetrator. But as discussed *infra*, people of color report significantly more disrespect and mistreatment during their birth experiences.[48] One study of court-ordered cesareans published in the New England Journal of Medicine found that people of color and immigrants were more likely to be subjected to court-ordered cesareans – 81% of the cases involved women identified as Black, Asian, or Hispanic; 24% did not speak English as a primary language.[49]

The factors that precipitate the conflict leading to threats may themselves be racialized. Frequently, the source of divergence between the individual's decisions about medical treatments and the physician's recommendations is the patient's religious or cultural beliefs. For instance, members of the Jehovah's Witnesses, a majority of whom are not white,[50] reject the use of blood transfusions, and have been subjected to proceedings to legally compel transfusions believed to be of benefit to the fetus.[51] In one case, a Black Jehovah's Witness was "yelled at and forcibly restrained, overpowered, and sedated" in order to be administered a blood transfusion doctors

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[43] *See, e.g.*, Meghan A. Bohren et al., *"By Slapping their Laps, the Patient will Know That You Truly Care for Her": A Qualitative Study on Social Norms and Acceptability of the Mistreatment of Women During Childbirth in Abuja, Nigeria*, 2 Soc. Sci. & Med. Population Health 640 (Dec. 2016).

[44] *See* Survivors of Symphysiotomy, *Report Submission to the United Nations Special Rapporteur on Violence Against Women* (2019), https://bit.ly/3GGhsm9.

[45] *See* Janet Gallagher, *Prenatal Invasions & Interventions: What's Wrong With Fetal Rights*, 10 Harv. Women's L.J. 9, 9-10 (1987).

[46] *See* Jefferson v. Griffin Spalding County Hospital Authority, 274 S.E.2d 457 (Ga. 1981).

[47] *See* Burton v. State, 49 So. 3d 263 (Fla. Dist. Ct. App. 2010). *See also*, In re A.C., 573 A.2d 1235, 1240-41 (1990) (Infant delivered via court-ordered cesarean died shortly after birth, and surgery contributed to the death of the mother.). It is easy to see how court-ordered bed rest to maintain pregnancy compliments a forced-pregnancy regime.

[48] Vedam et al., *The Giving Voice to Mothers Study*, *supra* note 10.

[49] Veronika Kolder, Janet Gallagher, & Michael T. Parsons, *Court-Ordered Obstetrical Interventions*, 316 New Eng. J. Med. 1192 (1987).

[50] Michael Lipka, *The Most and Least Racially Diverse U.S. Religious Groups*, PEW RSCH. CTR (July 27, 2015) https://pewrsr.ch/3rynT4s.

[51] In re Jamaica Hospital, 128 Misc. 2d 1006 (N.Y. Sup. Ct. Queens County, Apr. 22, 1985) (authorizing a blood transfusion over the religious objection of an 18-weeks pregnant Latina Jehovah's Witness). *But cf.*, In re Fetus Brown, 689 N.E.2d 397 (Ill. App. 1997)(reversing appointment of guardian ad litem with authority to approve unconsented transfusion for the benefit of the fetus); Mercy Hosp. v. Jackson, 489 A.2d 1130 (1985) (affirming trial court denial of hospital's petition for a guardian to consent to unwanted blood transfusion of a Jehovah's Witness for the benefit of her fetus), vacated as moot by Mercy Hosp. v. Jackson, 510 A.2d 562 (1986)

believed would help her fetus.[52] Muslims in the United States, like Jehovah's Witnesses, primarily identify as people of color, and also experience racialized threats in the context of childbirth.[53]One Black Muslim woman for example, declining cesarean surgery on the basis that "a Muslim woman has the right to decide whether or not to risk her own health to eliminate a possible risk to the life of her undelivered fetus," was forced to undergo surgery, on the basis of dire threats, with the court opining that "[a]ll that stood between the […] fetus and its independent existence, separate from its mother, was, put simply, a doctor's scalpel."[54] It's not hard to imagine people emboldened by the overturn of *Roe* making such threats and taking such action.

The obstetric violence emerging from pregnant patient's refusals based in their faith can also affect white birthing people who are members of religious minorities. An Orthodox Jewish Israeli woman in New York, who wished to avoid a third cesarean section because of her desire to preserve her ability have more children according to her faith's dictates, was forced to undergo cesarean surgery *without a legal process* when a hospital enforced its undisclosed policy of overriding the decisions of pregnant patients with viable fetuses.[55] Conversely, a Romanian woman narrowly avoided a court-ordered cesarean section in Illinois after having declined surgery on the basis of her religious belief in faith healing.[56] Her case was unusual in that she had the opportunity for development of the record, appellate review, and participation of civil rights advocates including the American Civil Liberties Union.[57] According to one survey, 88% of court orders for surgery were granted within six hours; 19% were granted within an hour, usually by telephone.[58] These examples illustrate how a racially-discriminatory system can nonetheless produce corresponding negative treatment for white people, especially due to the intersection of sex-based discrimination, "…white privilege is a double-edged sword…white privilege actively produces white disadvantage."[59]

Some of these hostile interactions between health care provider and patient are captured in reported case law; a much greater number of interactions never become reported case law simply because the threat is effective in coercing compliance.[60] This is especially so when the threat involved is removal of the child whom the birthing person is bringing into the world, as discussed in the next section.

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[52] In re Fetus Brown, 689 N.E.2d 397, 404 (Ill. App. 1997).
[53] Lipka, *The Most and Least Racially Diverse U.S. Religious Groups*, *supra* note 50.
[54] In re Madyun Fetus, 114 Daily Wash. L. Rptr. 2233 (D.C. Super. Ct. Oct. 29, 1986), *reported at* 573 A.2d 1259, 1262 (D.C. Sup. Ct. 1986).
[55] *Diaz-Tello, Invisible Wounds: Obstetric Violence in the United States*, *supra* note 33, at 57*; See Dray v. Staten Island Univ. Hosp.*, No. 500510/14 (N.Y. Sup. Ct. Dec. 15, 2015).
[56] In re Baby Boy Doe, 632 N.E.2d 326 (Ill. App. Ct. 1994).
[57] *Id.*
[58] Kolder et al, *Court-Ordered Obstetrical Interventions, supra* note 49, at 1195.
[59] Khiara Bridges, *Race, Pregnancy, and the Opioid Epidemic: White Privilege and the Criminalization of Opioid Use During Pregnancy*, 133 Harv. L. Rev. 770 (2020).
[60] Nancy K. Rhoden, *Cesareans and Samaritans*, 15 J. L. Med. & Health Care 118, 118 (1987); Theresa Morris & Joan H. Robinson, *Forced and Coerced Cesarean Sections in the United States*, 16 Contexts 24, 25-26 (2017) (noting that approximately one-third of the cases of forced or coerced cesarean examined in the study involved a birthing parent appealing a loss of parental rights).

b) Interventions Compelled by Threat of Family Regulation or Policing.

Among the coercive tactics used to induce compliance with medical advice is threatening to involve child welfare authorities[61]- a practice often referred to as "family regulation"[62] or "family policing."[63] This threat is effective because family regulation authorities do punish pregnant people through civil abuse and neglect cases for decisions they make about their pregnancy and birth.[64] It is worth noting that by responding to someone's medical decisions or behavior during labor with these coercive tactics, medical providers are stepping outside of their roles as caretakers, and making legal determinations and assessments of parental fitness – outside the scope of their role, responsibility, and expertise. This is particularly toxic when applied to Black and Indigenous people, who are already over-surveilled and over-represented within the family regulation system.[65] Using these coercive tactics renders medical providers part of a policing and surveillance system – fundamentally altering the patient-provider relationship, and deterring many from care.

Parents with disabilities and their families are also frequently, and often unnecessarily, referred into the family regulation system. Connie Conley-Jung and Rhoda Olkin found in a study of blind mothers that "Mothers with disabilities feel vulnerable about their parental rights and the custodial rights of parents with disabilities are frequently questioned solely on the basis of the parents' disabilities."[66] In fact, nearly all the parents with whom the National Council on Disability spoke for their *Rocking the Cradle* report stated that they lived in constant fear that they would eventually be reported because of their disability. This fear shapes people's medical decision-making. Kathryn, a new mother who is a wheelchair user and little person, told NCD that she is "always worried that some random stranger could call [CPS]."[67] Moreover, because of concern that their daughter's pediatrician will question their ability to parent, Kathryn and her husband, who has similar disabilities, always take a nondisabled person with them to appointments.[68] This story illustrates how the threat of family regulation not only has the potential to limit or alter people's healthcare options in the context of childbirth, but remains an ongoing fear that shapes the parenting decisions of many historically oppressed populations, including (but not limited to) Black, Brown and Indigenous people, people with disabilities, people who are experiencing poverty and people who have a history of incarceration.[69]

Legal precedent acknowledges that parents' right to make medical decisions on behalf of their children can be constrained when it threatens the child's health.[70] Due at least in part to the discriminatory conditions described in this brief, some people stretch this principle to mean pregnant people's right to make medical decisions about their pregnancy can be constrained

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[61] Kukura, *Birth Conflicts*, *supra* note 33 at 254-264.
[62] Roberts, *The Regulation of Black Families*, *supra* note 41.
[63] Dorothy Roberts, *Keynote: How I Became a Family Policing Abolitionist*, 11 Colum. J. Race & L. 455 (2021).
[64] *See id.*
[65] Children's Bureau of the Department of Health & Human Services, *Child Welfare Practice to Address Racial Disproportionality and Disparity*, at 2-3 (Apr. 2021), https://bit.ly/2UNTpNA.
[66] Connie Conley-Jung & Rhoda Olkin, *Mothers with Visual Impairments Who Are Raising Young Children*, 91 J. Visual Impairment & Blindness 15 (2001).
[67] National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children, Chapter 5: The Child Welfare System: Removal, Reunification, and Termination* (Sept. 27, 2011), https://bit.ly/3KwR92Z [hereinafter: "Nat'l Council on Disability, *Rocking the Cradle*"].
[68] *Id.*
[69] *See also*, Voluntary Resolution Agreement Between The United States Department of Health and Human Services and The State of Rhode Island Department of Children, Youth and Families, March 2022.
[70] Prince v. Massachusetts, 32 U.S. 158, 166-67 (1944).

when it threatens the fetus' health. Clearly, decision making about a child's health is different than decision making about a fetus' health, especially for the person gestating. For one thingfetal health cannot be guaranteed in any pregnancy, and the pregnant person is often not in control of the factors that determine health.[71] Furthermore, a person's decisions about how to give birth or lactate are not indicative of their ability to properly care for a child once born. In this context, the use of threats to coerce compliance is a form of discrimination under OCR's jurisdiction.

By invoking the threat of the family regulation system, health systems, facilities and providers suggest that fetuses are children to which they, through the state, can stand as ultimate parent (*parens patriae*), irrespective of the fundamental right to bodily self-determination of the pregnant parent, and the harm they face in unwanted medical intrusions. Unfortunately, the "mutual deference" afforded between family regulation authorities and health care providers frequently means that the fundamental rights at issue are given short shrift.[72]

The involvement of family regulation authorities in birthing may mean that a person's right to parent is dictated by how they cope with their labor and their willingness to accept the resulting state interference with their parenting. For example, a New Jersey woman, whose parental rights were ultimately terminated, was described by medical records as "erratic," "irrational," and "uncooperative" in the midst of active labor when she declined to pre-authorize cesarean delivery.[73] These notations seemingly failed to take into account that she was subjected to threats and psychiatric examinations because of her decisions while in labor.[74] Although the surgery was never needed and the baby was delivered healthy, the mother's unwillingness to fully submit to the numerous interventions demanded by the authorities became another reason to deny her right to parent her own child.[75] Questioning the psychological capacity of pregnant people is often part of these dynamics, creating a self-reinforcing feedback loop where lack of compliance indicates lack of psychological capacity which then invalidates lack of compliance and validates use of force.[76] Psychological evaluations themselves are often coerced. This illustrates the intersection of race and sex based stereotypes and how those stereotypes function to create a discriminatory effect.

When the Jewish woman in New York referenced above continued to decline surgery after being threatened with child welfare intervention, the hospital simply proceeded without her

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[71] *See e.g.,* Alex Kasman, et. al., *Association Between Preconception Paternal Health and Pregnancy Loss in the USA: An Analysis of US Claims Data,* 36 Hum. Reprod. 785 (2021).

[72] *Cf.* Clara Presler, *Mutual Deference Between Hospitals and Courts: How Mandated Reporting from Medical Providers Harms Families*, 11 Colum. J. Race & L. 733, 741 (2021) (Noting that, in child welfare cases related to living children, "when the issue is or appears to be medical, the court system does not function as the objective check the system envisioned it to be. Instead, he courts defer to the report absent a countering medical opinion [. . .] Deference [. . . renders] the legal system both impotent and complicit in the resulting harm.").

[73] N.J. Div. of Youth & Family Servs. v. V.M., 974 A.2d 448, 450-51 (N.J. Super. Ct. App. Div. 2009) (per curiam).

[74] *Id.* at 450-51.

[75] *Id.*

[76] *See for example*, the circular logic employed by Stated Island University Hospital with regard to their "Managing Maternal Refusals" policy which they contend validated the forced cesarean of Rinat Dray. They argue that, "Defendants respectfully submit that the subject policy, as a matter of law, cannot apply to a reasonable patient because a reasonable patient acting reasonably under the circumstances would consent to such treatment." Kristen Halford, Affirmation in Support of Cross-Motion and In Opposition to Plaintiff's Motion to Amend Her Complaint, ¶ 101 at 33 (2018).

consent.[77] It is therefore unsurprising that some birthing parents simply give in. As one mother explained, "I didn't fight because I knew that [family regulation authorities] would be an issue... I already had that fear put into me."[78] This is why the act of making the threats is a form of discrimination that requires redress in addition to the act of following through on the threats. While a parent may reasonably "give in" under these circumstances, and while the baby and the birthing person may be otherwise unharmed, the harm resulting from this form of discrimination remains and demands redress.

In some instances, the health care providers' stated concerns about the health of the child belie their true worry. For instance, a Florida woman who was nearly 39 weeks pregnant received a letter advising her the hospital intended to report her to the Department of Children and Family Services (which does not have jurisdiction over fetuses, but would have jurisdiction over her two children) because she declined a recommended elective cesarean section.[79] The letter was signed by the hospital's Chief Financial Officer, suggesting that the motivation was not a belief that she was abusing her children, but rather that she would sue for malpractice in the event of a complication.[80] But even a waiver of malpractice liability may be insufficient to stop such threats. Even after a Virginia woman — who had signed an acknowledgement of medical risks and waiver of liability — acquiesced to swearing and threats of court orders by her health care providers and delivered by cesarean, health care providers reported her to family regulation authorities.[81] This precipitated months of intrusive investigation before family regulation authorities dismissed the allegations as baseless.[82] Even investigations that do not lead to removal of the child from the family can deprive the infant-parent dyad of critical bonding time, the ability to establish breastfeeding,[83] and the dignity of the irreplaceable first moments of life.

The rights at stake – the ability to freely decide whether to undergo procedures that may carry serious immediate and long-term consequences, the ability to follow religious beliefs, the ability to have access to one's newborn – are fundamental. People should not be forced to litigate them in the midst of labor, or worse, retroactively after they have been violated. The Office for Civil Rights can and should ensure that these rights are enjoyed equally, by every pregnant person, without discrimination.

4. <u>The Pandemic Has Exacerbated and Exposed Inequities Stemming from Discrimination.</u>

From the outset of the COVID-19 pandemic, families have been reporting mistreatment by health care providers and human rights violations such as loss of labor support, separation

[77] Anemona Hartocollis, *Mother Accuses Doctors of Forcing a C-Section and Files Suit*, N.Y. TIMES (May 16, 2014), https://nyti.ms/2ISpnnV; Morris & Robinson, *Forced and Coerced Cesarean Sections in the United States*, *supra* note 60, at 26.
[78] Morris & Robinson, *Forced and Coerced Cesarean Sections in the United States*, *supra* note 60, at 26.
[79] *See* Diaz-Tello, *Invisible Wounds: Obstetric Violence in the United States*, *supra* note 33, at 56-57; Goodall v. Comprehensive Women's Health Ctr., No. 2:14-cv-399-FtM-38CM, 2014 WL 3587290 (M.D. Fla. July 18, 2014).
[80] See Morris & Robinson, *Forced and Coerced Cesarean Sections in the United States*," *supra* note 60, at 29 (The woman recounted, "the hospital's ...counsel basically said ...they would rather have a lawsuit against the hospital for ...doing physical harm to me for giving me a surgery against my will than having a litigation for something going wrong during my VBAC").
[81] Diaz-Tello, *Invisible Wounds: Obstetric Violence in the United States, supra* note 33, at 59; Kukura, *Birth Conflicts*, *supra* note 33, at 258-64. *See* Mitchell v. Brooks, No. CL13001773-00 (Va. Cir. Ct. Augusta County).
[82] Diaz-Tello, *Invisible Wounds: Obstetric Violence in the United States, supra* note 33, at 59.
[83] Kukura, *Birth Conflicts*, *supra* note 33, at 264.

from newborns, unwanted interventions, and lack of access to antenatal and postpartum care.[84] Despite international, state and local guidance that essential health care services must be maintained during COVID-19, and that human rights may not be eschewed, mistreatment, discrimination and human rights violations have been occurring nonetheless.[85]

Efforts to contain the spread of the coronavirus have led health care providers to depart from evidence-based practices and to justify discriminatory care by invoking the global health pandemic at the cost of basic decency and human rights. Advocacy organizations have documented these violations in the context of maternity care.[86] These violations include being denied the right to a companion during labor and birth, forced interventions during childbirth, forced inductions and cesarean surgeries without medical indication, separation from infants and interruption of breastfeeding, lack of access to care due to maternity site closures or understaffed facilities, and unsafe exposure to COVID-19 due to lack of personal protective equipment or overcrowded maternity wards.[87] In monitoring such violations, Human Rights in Childbirth (HriC) has noted that low-income and marginalized people have been disproportionately affected by these changes.[88] HRiC also identified the risk that COVID-19 is being used as an excuse in some settings to obscure medical malpractice, reflecting the broader concern that COVID-19 emergency measures are making ongoing rights violations invisible.[89] In response, several NGOs have tracked and reported on these failures with the hope that policy makers will correct-course, and guard against complacency and inaction. OCR is well-situated to play a role in this work. The following section describes the scope of OCR's legal authority to enforce federal nondiscrimination protections in the context of obstetric violence and obstetric racism, as well as promising procedural mechanisms that could be mobilized toward addressing them.

B. The Office for Civil Rights Has Both the Legal Authority and Procedural Mechanisms Necessary to Address Obstetric Racism and Obstetric Violence.

OCR can improve access to justice for survivors of obstetric racism and obstetric violence and prevent harmful discrimination. Before analyzing how obstetric racism and obstetric violence constitute a violation of each of our national civil rights laws, this section will explain both why, and how, OCR is able to address the problem. First, this section will provide

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[84] Saraswathi Vedam et al., *Transdisciplinary Imagination: Addressing Equity and Mistreatment in Perinatal Care*, 26 Maternal & Child Health J. 674 (2022); Anteneh Asefa, *The Impact of COVID-19 on the Provision of Respectful Maternity Care: Fndings from a Global Survey of Health Workers*, 35 Women & Birth 378 (2021); Michelle Sadler, Gonzalo Leiva, & Ibone Olza, *COVID-19 as a Risk Factor for Obstetric Violence*, 28 Sexual & Reprod. Health Matters 46 (2020); Rebecca Reingold, Isabel Barbosa, & Ranit Mishori. *Respectful maternity care in the context of COVID-19: A Human Rights Perspective*, 151 Int. J. Gynaecology & Obstetrics 319 (2020); Robbie Davis-Floyd, Kim Gutschow, & David A Schwartz, *Pregnancy, Birth and the COVID-19 Pandemic in the United States*, 39 Med. Anthropology 413 (2020).

[85] *See e.g.* Birth Rights Bar Association, *Challenges Facing Pregnant and Birthing People During COVID-19* (2020); Human Rights in Childbirth, *Human Rights Violations in Pregnancy, Birth and Postpartum During the COVID-19 Pandemic* (2020); Michelle Sadler, Gonzalo Leiva & Ibone Olza, *COVID-19 As a Risk Factor for Obstetric Violence*, 28 Reprod. Health Matters 1 (June 2020).

[86] HriC, *supra* note 85.

[87] *Id.* at 8-19; Elephant Circle, *Opportunity for a Paradigm Shift in Maternity Care: Guiding Principles for Getting the Most Out of COVID-19* (2020).

[88] HriC, *supra* note 85, at 9, 18.

[89] *Id*. at 19.

an overview of OCR's legal authority to address complaints of obstetric racism and violence. It will then map out how existing procedural mechanisms can be mobilized toward greater accountability for survivors of this mistreatment and abuse.

1. The Office for Civil Rights Has Legal Authority to Enforce Nondiscrimination Protections Against Perpetrators of Obstetric Racism and Violence.

The Office for Civil Rights (OCR) has a responsibility to enforce our nation's civil rights laws against perpetrators of obstetric racism and violence which may include health systems, facilities and providers. Section 42 USC 18116 and its implementing regulation (hereinafter "Section 1557") provide that an individual shall not be subjected to discrimination on the basis of race,[90] color,[91] national origin,[92] sex,[93] age,[94] or disability[95] while participating in any health program or activity, any part of which is receiving federal financial assistance.[96] OCR also has enforcement authority with respect to health programs and activities that receive federal financial assistance from the Department of Health and Human Services (HHS), or are administered by HHS or any entity established under Title I of the Affordable Care Act. This includes the Maternal Child Health Block Grant, which helps provide care for 92% of all pregnant people and 98% percent of infants.[97] This means that any acts of discrimination that are prohibited under Section 1557 may be investigated and addressed by OCR so long as they occur in any of the healthcare settings enumerated above.

This brief aims to locate the specific harms of obstetric racism and obstetric violence within the existing legal frameworks for each of the major civil rights laws that OCR enforces so that OCR can begin to understand and recognize obstetric racism and obstetric violence as forms of discrimination within its jurisdiction.[98] Once obstetric violence and obstetric racism are institutionally recognized as forms of discrimination that violate Section 1557, the agency has considerable authority to bolster accountability. The following section will enumerate the different procedural mechanisms through which OCR could review and investigate complaints of obstetric racism and violence.

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[90] Section 1557 of 42 USC 18116 prohibits discrimination on the grounds prohibited under Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d et seq. (race, color and national origin). *See* Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority, 85 Fed. Reg. 37160 (June 19, 2020).

[91] *Id.*

[92] *Id.*

[93] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of sex, as defined under Title IX of the Education Amendments of 1972, 20 U.S.C. 1681 et seq., which encompasses discrimination on the basis of pregnancy status. *See* U.S. Dept. of Educ., *Sex Discrimination: Overview of the Law*, (last accessed Sept. 3, 2021), https://www2.ed.gov/policy/rights/guid/ocr/sexoverview.html.

[94] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of age, as defined under the Age Discrimination Act of 1975, 42 U.S.C. 6101 et seq.

[95] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of disability, as defined under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794. *See* Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority, 85 Fed. Reg. 37160 (June 19, 2020).

[96] *See* Office for Civil Rights, *Discrimination on the Basis of Sex*, (last reviewed Apr. 1, 2022), https://bit.ly/3NJ3xzr.

[97] *See* Health Resources and Services Administration, *Title V Maternal and Child Health (MCH) Block Grant*, HHS.GOV (Dec. 1, 2020), https://bit.ly/3QKztFA.

[98] *See infra*, sections III – V, which will demonstrate how obstetric violence rises to the level of a civil rights violation under each of the major civil rights laws that OCR enforces.

2. The Office for Civil Rights Provides a Valuable Forum for Individual Complaints of Obstetric Racism and Violence.

One of the main obstacles standing in the way of accountability for obstetric racism and violence is that there are too few reporting mechanisms that have the potential to deliver any form of justice. However, OCR has an online system for filing complaints for civil rights violations that took place in a State or local government healthcare or social services agency.[99] This section will first provide an overview of the legal bases upon which OCR may review complaints through its online portal, and then elaborate upon the virtues of this complaints mechanism compared to the others to which survivors of obstetric racism and violence currently have access.

a) OCR's Legal Authority to Review Individual Complaints of Discrimination that Fall Within Section 1557 Makes It a Promising Venue for Complaints of Obstetric Racism and Violence.

According to its authorizing statute, OCR has the delegated legal authority to "facilitate and coordinate the Department of Health and Human Services' enforcement of the Federal conscience and anti-discrimination laws."[100] This enforcement power encompasses the authority to receive, investigate, and seek resolution of healthcare discrimination complaints arising under Section 1557 of 42 UUSC 18116. This provision prohibits discrimination as defined in:

i. Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d et seq., which prohibits discrimination on the basis of race, color and national origin.
ii. Title IX of the Education Amendments of 1972, 20 U.S.C. 1681 et seq., which encompasses discrimination on the basis of pregnancy status.
iii. The Age Discrimination Act of 1975, 42 U.S.C. 6101 et seq, which prohibits discrimination on the basis of age.
iv. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, which prohibits discrimination on the basis of disability.

Because obstetric racism and violence are forms of discrimination on the basis of one or several of these protected characteristics, the agency has legal authority to investigate and seek resolution of complaints through the portal. The following section will provide an overview of some of the reasons why a survivor might choose to seek justice through the portal rather than through other mechanisms of redress.

[99] Office for Civil Rights, *Filing a Civil Rights Complaint,* HHS.GOV (last reviewed Mar. 17, 2020) https://bit.ly/3zD1jxu.
[100] *See* Enforcement Authority, 45 CFR § 88.7 (2019).

b) OCR's Individual Complaints Mechanism Has Several Features that Make it a Promising Venue for Complaints of Obstetric Racism and Violence.

The complaints portal is a valuable forum for survivors of obstetric racism and violence for a variety of reasons. First, the portal is accessible online, free and available to the public. By eliminating cost barriers and the need for a lawyer, the portal eliminates two significant (and often insurmountable) barriers for redress of these harms.

Second, someone other than the birthing person themselves can file the complaint. The website provides "if you believe that you have been discriminated against because of your race, color, national origin, disability, age, sex or religion in programs or activities that HHS directly operates or to which HHS provides federal financial assistance, you may file a complaint with OCR. You may file a complaint for yourself or someone else."[101] This means that the birthing person would not have to bear the brunt of assembling the complaint if they did not wish to do so: A loved one, doula, patient advocate, or other support person could file a complaint on their behalf. This is an attractive feature, given that complaints must be filed within 180 days of the abuse. Survivors of obstetric racism and violence are confronted with the challenges of the postpartum period during that same time, as well as recovering from the trauma of the birthing experience itself (this timeline is still a barrier, which we will discuss further below).

Third, the portal does not create the same administrative or evidentiary challenges that complaints mechanisms in the traditional judicial system or Medical Licensing Boards have. Currently people can file complaints without needing to submit additional evidence of what happened to them—this makes OCR process preferable to the complaint process at many state licensing boards, which tend to require evidence that is rarely available to individuals in obstetric racism violence cases, or that is narrowly focused on clinical and not civil rights priorities.[102]

Fourth, the OCR is not as constrained by local factors that can limit accountability. Local factors can include a hospital or Medical Board that is hostile to the complainant or simply ignorant about national standards. Relationships between powerful decision-makers locally are often so close as to make neutral consideration of a complaint by locally situated authorities impossible. People may even decline to pursue local action because of the complex dynamics and interconnected relationships at play. This, combined with the factors enumerated above, make the complaints portal an attractive alternative to litigation or other existing complaints mechanisms.

3. <u>In Addition to Reviewing Individualized Complaints for Civil Rights Abuse in Healthcare Settings, OCR May Use These Enforcement Mechanisms.</u>

In addition to reviewing individualized complaints for civil rights abuse in healthcare settings (elaborated below), OCR has additional enforcement mechanisms at its disposal. These include those which are provided for and available under Title IX when enforcing Section 1557's prohibition on sex discrimination.[103] These can be found at 45 C.F.R. 86.71, which adopts the procedures at 54 C.F.R. §§ 80.6 through 80.11 and 45 C.F.R. Part 81. These are broken down

[101] *See* Enforcement Authority, 45 CFR § 88.7 (2019).
[102] Rebecca Dekker, *EBB 170 – Addressing Mistreatment in Childbirth Care with Birth Monopoly Founder, Cristina Pascucci*, EVIDENCE BASED BIRTH PODCAST (Mar. 31, 2021), https://evidencebasedbirth.com/addressing-mistreatment-in-childbirth-care-with-birth-monopoly-founder-cristen-pascucci/.
[103] 45 C.F.R. § 92.5(a).

into four main mechanisms: (1) cooperation and assistance, (2) compliance reports, (3) access to sources of information, and (4) information to beneficiaries and participants.[104]

a) Cooperation and Assistance

The responsible Department official at OCR "shall to the fullest extent practicable seek the cooperation of recipients" and "shall provide assistance and guidance to recipients to help them comply."[105] This means that OCR has an obligation to actively engage facilities that receive federal funding in the work of combatting obstetric racism and violence, and provide them with guidance to about what these harms are, and their responsibilities to prevent and provide redress for them.

b) Compliance Reports

All federally-funded healthcare institutions "shall keep such records and submit to the responsible Department official or his designee timely, complete and accurate compliance reports at such times, and in such form and containing such information, as the responsible Department official or his designee may determine to be necessary to enable him to ascertain whether the recipient has complied or is complying with this part."[106] Therefore, OCR can require recipients to measure instances of obstetric racism and violence and report incidents and prevalence to the Department. This is a particularly important power since incidents are not otherwise being tracked or reported, other than by individual researchers who only assess facilities who agree to participate.

c) Access to Sources of Information

Each funding recipient must grant access by the responsible Department official or designee during normal business hours to any of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with the law.[107] Therefore, OCR has the authority to investigate hospitals and hospital records for compliance with its obligations to prevent obstetric racism and violence and hold providers accountable for it.

d) Information to Beneficiaries and Participants

Each funding recipient "shall make available to participants, beneficiaries, and other interested persons such information regarding the provisions of the law and its applicability to the program for which the recipient receives Federal financial assistance and make such information available to them in such manner, as the responsible Department official finds necessary to apprise such persons of the protections against discrimination assured them by the Act and this regulation."[108] This means that OCR may

[104] 45 C.F.R. § 92.5(a).
[105] 45 CFR § 80.6(a).
[106] 45 CFR § 80.6(b).
[107] *See* 45 CFR § 80.6(c).
[108] 45 CFR § 80.6(d).

require hospitals to inform pregnant and birthing people of their rights to be free from discrimination. This power is critical since many people do not yet know that they are entitled to freedom from discrimination during pregnancy and birth.

Each of these mechanisms provides alternative pathways for OCR to address obstetric racism and violence that do not require survivors to make individual complaints. In this sense, the agency need not wait to receive individual complaints in order to act. Rather, the agency must begin to formally recognize obstetric racism and violence as civil rights violations. The following sections will provide a roadmap for how and why obstetric violence and obstetric racism is discrimination under each of the civil rights laws that OCR enforces.

II. Discrimination on the Basis of Race, Color, and National Origin Is Widespread in Perinatal Care and OCR Has the Authority to Address It.

Programs that receive federal funds cannot distinguish (either directly or indirectly) among individuals on the basis of race, color or national origin in the quality or timeliness of program services.[109] Significant data now documents that birthing people of color are receiving lower quality care from health systems, facilities and providers on the basis of their race, including the United States Commission on Civil Rights.[110] Birthing people of color are twice as likely to experience untimely care or care denials,[111] and twice as likely to experience disrespectful or violent care than white birthing people.[112] A 2019 cross-sectional survey of 2,700 people who had given birth found that Indigenous birthing people were the most likely to report experiencing at least one form of mistreatment by healthcare providers (32.8%). They were closely followed by Latine/x (25.0%) and Black birthing people (22.5%).[113] White respondents were least likely to report having experienced mistreatment but were also not free from harm (14.1%).[114] These disparities are not random: They are the consequences of a long legacy of discrimination on the basis of race, color and national origin that OCR explicitly prohibits. The fact that some white people experience these harms as well does not eliminate its racially discriminatory underpinnings and may also be due to another interconnected dimension of discrimination (sex, age, disability) discussed below.[115]

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[109] *See* Office for Civil Rights, *Civil Rights Requirements Title VI of the Civil Rights Act*, HHS.GOV (Jul. 26, 2013), https://bit.ly/3bsNLKT, *citing* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).

[110] U.S. Commission on Civil Rights, 2021 Statutory Enforcement Report: Racial Disparities in Maternal Health, September, 2021.

[111] A 2019 study of 2,138 birthing people found that Black, Latine/x, Asian, and Indigenous birthing people were twice as likely as White birthing people to report that a health care provider ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time. *See* Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10, at 85.

[112] *See id.; see also* Logan et al., *Coercion and Non-Consent During Birth and Newborn Care in the United States*, *supra* note 24.

[113] *See id.*

[114] *See id.*

[115] *See* Bridges, *Race, Pregnancy, and the Opioid Epidemic*, *supra* note 59 (providing an explanation of how white privilege can nonetheless lead to white people experiencing harms).

For example, under Title VI, a healthcare provider that receives federal funding may not "provide services or benefits in a different manner from those provided to others under the program" on the basis of race.[116] OCR's website specifically states that it has enforcement authority over complaints of disparate treatment of this nature.[117] Currently, twice as many Latine/x and Indigenous birthing people reported that health care providers shouted at or scolded them compared to white birthing people.[118] This is undeniable evidence that providers are- whether they are aware of it or not- treating Latine/x and Indigenous birthing people "in a different manner" on the basis of their race, color or national origin. Therefore, OCR could act to provide redress in instances where evidence reveals a pattern of health systems, facilities or providers administering perinatal care in a different or disparate manner to Indigenous and Latine/x birthing people than they do to white birthing people. Likewise, Black, Latine/x, Asian, and Indigenous birthing people were twice as likely as white birthing people to report that a health care provider ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time.[119] Not only do these behaviors cause their own, emotional harm, but they also contribute to negative outcomes both for the birthing person and their infant.[120] This will be discussed in greater detail below, but it is important to recognize how these forms of discrimination contribute to the reality that America's maternal mortality rate is higher for Black and Indigenous people than white people, and rising.[121]

These stark disparities reveal the prevalence of discrimination on the basis of race, ethnicity and national origin in the context of pregnancy and childbirth. Often misconstrued as a "failure to provide culturally competent care," and misunderstood as a strictly clinical phenomenon rather than one with institutional and structural dimensions, this discrimination can take a variety of different forms such as (but not limited to) physical abuse, non-consensual care, non-confidential care, discriminatory or non-dignified care, and neglectful or untimely care.[122] Each disproportionately impacts birthing people of color in the U.S. and constitutes a violation of Title IV's safeguards against differential treatment on the basis of race, color or national origin.

It is important to note that people experience discrimination through intersecting positions and identities. In addition to race and sex, national origin, age, disability, gender expression, body mass index, and experiences with incarceration or substance use can contribute to and exacerbate the discrimination people experience during pregnancy and birth as we will discuss in more detail below. While the national civil rights laws fail to adequately address the nature of these intersections, OCR can be attuned to- and appreciate- that someone may experience discrimination that is recognized by several civil rights laws at once, others may

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[116] Office for Civil Rights, *Discrimination on the Basis of Race, Color or National Origin,* HHS.GOV (last reviewed Dec. 13, 2015)., https://bit.ly/3mHE11B.
[117] *Id.*
[118] *See* Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10 at 85.
[119] *See* Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10 at 85.
[120] Centers for Disease Control & Prevention, *Working Together to Reduce Black Maternal Mortality* (Apr. 2021), https://bit.ly/3HoA9wa.
[121] *Id.*
[122] *See* Muhabaw Shumye Mihret, *Obstetric Violence and Its Associated Factors Among Postnatal Women in a Specialized Comprehensive Hospital, Amhara Region, Northwest Ethiopia*, 12 BMC Res. Notes 600 (2019); *see also* Elizabeth Kukura, *Obstetric Violence*, 106 Geo. L.J. 721, 728 (2018).

experience discrimination that is not recognized by civil rights law, or experiences of discrimination may be compounded by discriminatory treatment that occurs across several dimensions.

Because of the complex interplay of discrimination across dimensions people may not identify what they have experienced as a form of discrimination or may identify one dimension of discrimination but not others. This is why it is particularly important for OCR to be attuned to the range of possible dimensions and to help identify pathways of accountability across them. In addition, because of the nature of pregnancy and birth as experiences that impact multiple generations at once, it is a particularly critical site of civil rights intervention.

A. Obstetric Racism Is Rooted in a Historic Legacy of Oppression and Violence Targeting Black Americans.

Dating to its origins in slavery, the specialty of obstetrics and gynecology (OBGYN) played a foundational role in medical racism in the United States.[123] OBGYN research produced and naturalized racial differences, with the result that such differences became focal points for operationalizing racism.[124] As examples of *obstetric racism*, OBGYN researchers refined experimental surgeries on enslaved people with childbearing capacity and controlled the fertility of racialized minorities, as in the forced sterilizations of Mexican-American immigrant women.[125] The dominant ethics, science, and leadership in perinatal quality improvement (QI) that exists today continuously deny the role of racism in Black birthing people's perinatal deaths (60-70 percent of perinatal deaths are preventable) instead focusing on clinical dimensions of differences that reinforce the lie that race is a biological construct.[126]

In response, the PREM-OB Scale™ was created to translate obstetric racism into examples of harmful clinical practices and policies using cultural rigor methodology, as defined and refined for, by, and with Black birthing people as patient, community, and content experts.[127] This scale challenges the daily denial of the occurrence of obstetric racism in the public health literature as well as in perinatal quality improvement (QI) literature, and creates an opportunity for QI leaders, hospitals, and health plans to take responsibility for the deplorable services and conditions in which US hospitals "handle," rather than care for, Black women and

[123] *See generally* Deirdre Cooper Owens, *Medical Bondage: Race, Gender and the Origins of American Gynecology* (Univ. of Georgia Press, 2017).
[124] *See generally* Harriet Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (Anchor, 2008).
[125] Alexandra Minna Stern, *Sterilized in the Name of Public Health: Race Immigration and Reproductive Control in Modern California*., 95 Am. J. Pub. Health 1128 (July 2005); Cooper Owens, *supra* note 123; Davis, *Obstetric Racism, supra* note 18.
[126] Rachel Hardeman, J'Mag Karbeah & Katy Kozhimannil, *Applying a Critical Race Lens to Relationship-Centered Care in Pregnancy and Childbirth: An Antidote to Structural Racism*, 47 Birth 3 (2020); Jonathan Metzl & Dorothy Roberts, *Structural Competency Meets Structural Racism: Race, Politics, and the Structure of Medical Knowledge*, 16 AMA J. of Ethics 674 (2014); Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*, at 433 (The New Press, 2011).
[127] *See* e.g. Davis, *Reproducing While Black, supra* note 18, Scott, *The Rise of Black Feminist Intellectual Thought and Political Activism in Perinatal Quality Improvement, supra* note 25; Scott & Davis, *Obstetric Racism, supra* note 25; Emily White VanGompel et al., *Psychometric Validation of a Patient-Reported Experience Measure of Obstetric Racism© (The PREM-OB Scale™ suite*), 00 Birth 1 (2022).

TGD individuals.[128] This tool also provides an opportunity for OCR to both hold systems accountable and offer a tool for oversight and quality improvement centered on undoing racism.

Obstetric racism is the result of slavery's legacy. Slavery established a "racial calculus" that devalues Black lives, and this devaluation of Black lives remains in the "afterlife of slavery" as demonstrated by "skewed life changes, limited access to health and education, premature death, incarceration, and impoverishment."[129] Davis writes:

> Conceptually the afterlife is not simply a consequential expression of inheritable trauma. In other words, it is not that the afterlife of slavery has not resulted in an epigenetic phenomenon (it may). Instead, it is that one way Black women's prenatal experience, pregnancy, and birthing can be understood is an extension of tropes, practices, and beliefs that can be traced back to antebellum and postbellum periods. What we see is that racism is continuously recalibrated – a racism that is a reinterpretation of enduring processes of slavery.[130]

Inequities in maternal health outcomes are one way that this discriminatory structure is manifest, but it is also manifest in a range of experiences that can be perceived and measured. The following section will trace some of the concrete ways in which contemporary clinical practices, patient risk assessment tools, and distribution of perinatal services perpetuate obstetric racism and racist discrimination more broadly against birthing people of color.

1. Modern Day Clinical Practices Perpetuate Structural Racism in Perinatal Health.

While all profess to have the goal of quality care and valuing patient choice and autonomy, different philosophies and goals of care and practice between patients and providers often impede the preservation of human rights in childbirth.[131] This is especially true when differing conceptions of risk are involved.[132] This underscores the need for enforcement of civil rights laws in the context of pregnancy and birth. As mentioned above, Dr. Davis has delineated six dimensions of obstetric racism: diagnostic lapses; medical abuse; intentionally causing pain;

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[128] *See* Scott, *The Rise of Black Feminist Intellectual Thought and Political Activism in Perinatal Quality Improvement*, *supra* note 25.

[129] Lewis Miles, *The Afterlife of Slavery: How Racial Logics Maintain Racial Health Disparities*, INTERDISCIPLINARY ASS'N FOR POPULATION HEALTH SCI. (2019), https://bit.ly/3xKsm8E; Saidiya Hartman, *The Belly of the World: A Note on Black Women's Labors*, 18 Souls 166 (2016).

[130] Dána-Ain Davis, *Reproductive Injustice: Racism, Pregnancy and Premature Birth*, at 15 (NYU Press, 2019).

[131] Wendy Hall, Jocelyn Tomkinson & Michael Klein, *Canadian Care Providers' and Pregnant Women's Approaches to Managing Birth: Minimizing Risk While Maximizing Integrity*, 22 Qualitative Health Rsch. 575 (2012); Sandra Healy, Eileen Humphreys & Catriona Kennedy, *Midwives' and Obstetricians' Perceptions of Risk and Its Impact on Clinical Practice and Decision-Making in Labour: An Integrative Review*, 29 Women Birth 107 (2015); Darie Daemers et al., *Factors Influencing the Clinical Decision-Making of Midwives: A Qualitative Study*, 17 BMC Pregnancy & Childbirth 345 (2017).

[132] Lesley Barclay et al., *Reconceptualising Risk: Perceptions of Risk in Rural and Remote Maternity Service Planning*, 38 Midwifery 63 (2016); Melissa Cheyney, Courtney Everson & Paul Burcher, *Homebirth Transfers in the United States: Narratives of Risk, Fear and Mutual Accommodation,* 24 Qualitative Health Rsch. 443 (2014); Soo Downe, et al., *What Matters to Women: A Systematic Scoping Review to Identify the Processes and Outcomes of Antenatal Care Provision That Are Important to Healthy Pregnant Women*, 123 Brit. J. of Obstetrics & Gyneacology 529 (2016); Soo Downe, Kenny Finlayson, & Anita Fleming, *Creating a Collaborative Culture in Maternity Care*, 55 J. Midwifery Women's Health 250 (May 2010); Soo Downe, Denis Walsh & Gill Gyte, *Is Maternity Care Evidence Based or Interpretation Driven? Place of Birth as an Exemplar*, 24 Midwifery 247 (Sept. 2008).

coercion; neglect, dismissiveness or disrespect; and ceremonies of degradation.[133] This section will analyze how discriminatory beliefs surrounding race underly each of these forms of mistreatment, thereby illustrating the risk conception Black perinatal patients encounter.

Diagnostic lapses occur when a clinicians' uninterrogated belief that Blackness is pathological leads them to de-emphasize, exaggerate or ignore a patient's symptoms resulting in an inappropriate or lapsed diagnosis. This discriminatory response is based on impermissible stereotypes about what Black people are susceptible and immune to.[134] For instance, when a woman is presumed to have high blood pressure because she is Black and is told she will need a C-Section.

Medical abuse occurs when medical professionals engage in experimentation and/or (repetitive) behavior that is motivated not by concern for the patient but by a drive to validate the clinician's self-worth and uphold their domination over the patient.[135] Historically, Black bodies have been used in the service of experimentation and causing harm, for instance the history of sterilization or the Mississippi Appendectomy.[136] This form of discrimination is based on racialized beliefs about pain immunity and as well as the absence of empathy to reduce Black suffering.[137] This includes obstetric hardiness, the belief that Black birthing people have high pain tolerance during birthing, and manifests as intentionally causing pain or failing to appropriately manage pain.[138]

Coercion occurs when medical professionals perform procedures without consent and/or intimidate patients to make decisions, such as telling a patient their baby will be harmed if they don't have a particular procedure.[139] As described in more detail below, when this occurs it is both a discriminatory tactic and has a discriminatory effect since cesarean surgery increases negative health outcomes.

Neglect, dismissiveness, and disrespect occur when medical professionals do not pay attention to a person in need of reproductive care and/or treats them with disdain.[140] Like coercion this is both a discriminatory tactic and has a discriminatory effect, since neglect and disrespect correlate with negative health outcomes.[141]

Ceremonies of degradation are the ritualistic ways in which patients are humiliated or shamed and includes a sense of being sized up to determine the worthiness of the patient (or their support persons) who may be viewed as a threat.[142] In response, medical staff may deploy security, police, social services or psychiatry to ensure compliance or to remove the

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[133] Davis, *Reproducing While Black*, *supra* note 19.
[134] Dána-Ain Davis, Cheyenne Varner, Leconté J. Dill, *A Birth Story*, ANTHROPOLOGY NEWS (Aug. 27, 2021), https://bit.ly/3y02Agw.
[135] Dána-Ain Davis, Cheyenne Varner, Leconté J. Dill, *A Birth Story*, ANTHROPOLOGY NEWS (Aug. 27, 2021), https://bit.ly/3y02Agw.
[136] *See* Kidi Tafesse, *What the 'Mississippi Appendectomy' Says About the Regard of the State Towards the Agency of Black Women's Bodies*, MOVEMENT FOR BLACK WOMEN'S LIVES (May 1, 2019), https://bit.ly/3MSUtH2.
[137] *See id.*
[138] *See* Colleen Campbell, *Medical Violence, Obstetric Racism, and the Limits of Informed Consent for Black Women*, 26 Mich. J. Race & L. 47 (2021).
[139] Logan et al., *Coercion and Non-Consent During Birth and Newborn Care in the United States*, *supra* note 24.
[140] Davis, Varner & Dill, *A Birth Story*, *supra* note 134.
[141] Jane Sandall et al., *Short-term and Long-term Effects of Caesarean Section on the Health of Women and Children*, 392 The Lancet 1349 (Oct. 2018); Jonathan M. Snowden et al., *Cesarean Birth and Maternal Morbidity Among Black Women and White Women After Implementation of a Blended Payment Policy*, 55 Health Serv Res. 729 (Oct. 2020).
[142] *See* Davis, *Reproducing While Black*, *supra* note 19.

"threatening" person. Evidence of such a response to a birthing person is always worth a second look for discrimination because none of these tactics have any clinical purpose or value. Often these tactics are employed by medical professionals with the support of the facilities and health systems that they work within, bringing additional force and significance to these actions.

Furthermore, the strategies Black families use to avoid or mitigate racist encounters are often used by providers and facilities to justify further medical abuse, coercion, neglect, or degradation.[143] These strategies include: "racial reconnaissance," being hypervigilant about procedures and finding providers that meet their needs and their requirements for support; "refusal" which goes beyond not doing something, and includes concern about the context and conditions of agreeing to do something (this might include choosing a homebirth in an effort to create something autonomous); and "resistance" which is an act of mobilization against a system and can involve questioning the terms of intervention and negotiating various forms of involvement in decision making, it is rooted in having a vision of how one wants to be treated based on their own terms; an unwillingness to disappear.

2. Modern Day Perinatal Risk Assessment Tools are Marred by Racist Stereotypes: The VBAC Calculator as an Example of Race-Based Discrimination under OCR's Jurisdiction.

Contemporary risk assessment tools in pregnancy and childbirth continue to perpetuate racist stereotypes. This section will provide an in-depth analysis of one such tool- the Maternal Fetal Medicine Units (MFM) Vaginal Birth After Cesarean Success Calculator (hereinafter VBAC Calculator)- and demonstrate how it manifests as race-based discrimination against Black and Latine/x people with the capacity for pregnancy deployed by health systems, facilities and providers within OCR's jurisdiction.

(a) The VBAC Calculator's Origins Are Rooted in Racially Discriminatory Views.

To understand why the VBAC calculator is another example of obstetric racism, we must first understand its origins as a potential solution to the problem of cesarean overuse in the United States. Over the last 20 years, the United States has witnessed a sharp increase in cesarean use, now accounting for one in three births, or 1.2 million per year.[144] At 31.7% the US cesarean rate as of 2020[145] is noticeably more than twice the rate of 10-15% as recommended by the World Health Organization.[146] The U.S. cesarean rate is sustained by increases in primary, first-time cesareans and decreases in the number of birthing people attempting a vaginal birth after cesarean (hereinafter VBAC). Down from a peak of 28% in the late 1990s,[147] the VBAC rate is persistently inadequate, at 13.8%.[148]

With each subsequent cesarean, maternal and neonatal morbidity and mortality increase due to complications like abnormal placental implantation, pre-term birth, postpartum

[143] *See* Davis, *Reproducing While Black*, *supra* note 19.
[144] Centers for Disease Control & Prevention, *National Vital Statistics Reports: Births, Final Data for 2019* (2020).
[145] *Id.*
[146] World Health Organization, *Statement on Cesarean Section Rates* (2015), https://bit.ly/3MQUBH1.
[147] F. Gary Cunningham, et al., *NIH Consensus Development Conference Draft Statement on Vaginal Birth After Cesarean: New Insights*, 115 Obstetrics & Gynecology 1279 (Mar. 2010).
[148] Centers for Disease Control & Prevention,, *Recent Trends in Vaginal Birth After Cesarean Delivery: United States, 2016-2018* (Mar. 2020), https://bit.ly/39rGCJW.

hemorrhage, and surgical scar tissue.[149] Cesarean overuse has negatively impacted outcomes for all racial/ethnic groups, and the United States' high maternal mortality and morbidity rates are already the worst among industrialized nations.[150] Even in California, the state that leads the nation in reducing avoidable maternal morbidity and mortality, 37% of the rise in maternal morbidity across all groups over the last 20 years can be explained by cesarean surgery, with Black birthing people most seriously affected.[151]

As a result, in a 2010 consensus statement the National Institutes of Health (NIH) declared increasing the VBAC rate to be a public health priority.[152] Researchers endeavored to develop an accurate VBAC prediction model to support clinicians in identifying those candidates with the highest chance for a successful VBAC.[153] The reasoning followed that if only those VBAC candidates with the highest probability for a successful VBAC went onto attempt VBACs, then the VBAC rate might increase, assuming that some percentage of "good" candidates for VBAC were currently undergoing repeat cesareans.[154] One VBAC prediction tool rose to prominence in the United States: the MFMU VBAC Calculator. The VBAC calculator predicted the probability for a successful VBAC by combining an individual's clinical history, like the indication for the prior cesarean, with a pregnant person's age, Body Mass Index (BMI)[155], and their race or ethnicity, categorized by only these three options: White, Black, or Hispanic. When comparing these three racial/ethnic groups, the calculator gave Black and Latine/x pregnant people probabilities for a successful VBAC that were on average 5-15 points lower than White pregnant people.[156]

Like past forms of obstetric racism, the VBAC calculator considered race and ethnicity to be markers of an intrinsic health difference between human populations.[157] Certain approaches to epidemiology supported the application of race as a population risk factor to the study of obstetric outcomes.[158] However, this race-as-a-risk-factor approach differs from that of critical-race scholars who have advanced an empiric argument that racism, as a pervasive social process that structures access to health and wealth, is the risk factor that produces disparate health outcomes, including possibly differential VBAC rates.[159] A new version of the VBAC calculator

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[149] Jane Sandall, et al., *Short-Term and Long-Term Effects of Caesarean Section on the Health of Women and Children*, 392 The Lancet 1349 (Oct. 2018).
[150] Nicholas J. Kassebaum, et al., *Global, Regional, and National Levels and Causes of Maternal Mortality During 1990-2013: A Systematic Analysis of the Global Burden of Disease Study 2013*, 384 The Lancet 98 (2014).
[151] Stephani Leonard, Elliott Main & Susan Carmichael, *The Contribution of Maternal Characteristics and Cesarean Delivery to an Increasing Trend of Severe Maternal Morbidity*, 19 BMC Pregnancy and Childbirth 16 (2019).
[152] *See* F. Gary Cunningham, et al., *NIH Consensus Development Conference Draft Statement on Vaginal Birth After Cesarean: New Insights*, 115 Obstetrics & Gynecology 1279 (2010).
[153] *Id.*
[154] Torri Metz, et al., *How Do Good Candidates for Trial of Labor After Cesarean (TOLAC) Who Undergo Elective Repeat Cesarean Differ From Those Who Choose TOLAC?* 208 Am. J. Obstetrics & Gynecology e451 (2013).
[155] Body Mass Index is in itself a discriminatory tool, *see for example*, Sabrina Strings, *Fearing the Black Body: The Racial Origins of Fat Phobia* (NYU Press, 2019).
[156] William Grobman, et al. *Development of a Nomogram for Prediction of Vaginal Birth After Cesarean Delivery*, 109 Obstetrics & Gynecoology 806 (2007).
[157] Scott & Davis, *Obstetric Racism*, *supra* note 25.
[158] Osagie Obasogie, et al., *Race in the Life Sciences: An Empirical Assessment, 1950-2000*, 83 Fordham L. Rev. 3089 (2015).
[159] Joia Crear-Perry et al., *Social and Structural Determinants of Health Inequities in Maternal Health.*, 30 J. of Womens Health 230 (Feb. 2021).

that does not explicitly factor in race/ethnicity has been published[160]; however, it remains to be seen whether removing race as an explicit risk factor will fully address the possibility for implicit racism in the new calculator.[161]

(b)Contemporary Usage of the VBAC Calculator Has a Disproportionately Negative Impact on the Health and Wellbeing of Black Birthing People.

As a result of the VBAC calculator's discriminatory use of race as a risk factor, Black and Latine/x pregnant people, who had undergone a prior cesarean and were interested in a VBAC for their next pregnancies, were steered toward or outright forced to undergo repeat surgical births due to a perceived low calculator score.[162] According to the most comprehensive survey to investigate the VBAC calculator's use, gathered from a national sample of Certified Nurse Midwives (CNMs), 40% of practices required that the calculator be used and 1 in 5 CNMs reported that calculator scores were used to discourage or prohibit VBACs.[163]Some labor and birth units developed official policies denying patients who had calculator scores below 60% from attempting a VBAC. Providers used the MFMU's scientific studies and national ACOG guidelines to justify this 60% cutoff.[164] Because Black and Latine/x birthing individuals were more likely to fall below the 60% cutoff, blanket policies denying VBAC below a certain score disproportionately impacted these individuals. Thus, providers used the VBAC calculator to produce racially segregated outcomes in officially desegregated birth facilities.[165]

Evidence shows that after a first cesarean Black and Latine/x birthing people on average are more interested in attempting a VBAC compared to White birthing people (%interest in VBAC: Black 75%; Hispanic 54%; White 43%). The deeply personal factors that birthing individuals weigh when considering a VBAC or a repeat cesarean include whether the first cesarean had been a difficult recovery, having a desire to experience a vaginal birth, or planning a larger family.[166] The cruel irony of the VBAC calculator was that it removed safe birth options from VBAC-interested Black and Latine/x individuals who may also be the most interested in planning a VBAC.

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[160] William Grobman et al., *Prediction of Vaginal Birth After Cesarean Delivery in Term Gestations: A Calculator Without Race and Ethnicity*, 225 Am. J. of Obstetetrics & Gynecology 664.e1 (2021).
[161] Nicholas A. Rubashkin, *Why Equitable Access to Vaginal Birth Requires the Abolition of Race-Based Medicine*, 24 AMA J. of Ethics e233 (2022).
[162] Nicholas Rubashkin, *The MFMU VBAC Success Calculator: Statistical Prediction and Race in an Ethnography of Obstetric Thinking*, PhD Dissertation (2021) [hereinafter "Rubashkin, *The MFMU VBAC Success Calculator*"]; *see also* Priska Neely & Julia Simon, *Reproducing Racism*, REVEAL NEWS (May 23, 2020), https://bit.ly/3MVIzvU.
[163] Patrick D. Thornton, et al., *Calculators Estimating the Likelihood of Vaginal Birth After Cesarean: Uses and Perceptions*, 65 J.of Midwifery & Womens Health 621 (Sept. 2020).
[164] Rubashkin, *The MFMU VBAC Success Calculator*, *supra* note 162; *see also* William Grobman et al., *Can a Prediction Model for Vaginal Birth After Cesarean Also Predict the Probability of Morbidity Related to a Trial of Labor?*, 200 Am. J. of Obstetetrics & Gynecology e51 (2009); *see also* American College of Obstetricians & Gynecologists, *Practice Bulletin No. 115: Vaginal Birth After Previous Cesarean Delivery*, 116 Obstetrics & Gynecology 450 (2010).
[165] *See* Rubashkin, *The MFMU VBAC Success Calculator*, *supra* note 162.
[166] Laura Attanasio, Katy Kozhimannil & Kristen Kjerulff, *Women's Preference for Vaginal Birth After a First Delivery by Cesarean*, 46 Birth 51 (2019).

(c) Contemporary Usage of the VBAC Calculator Constitutes Unlawful Discrimination that OCR Has Authority to Address.

The VBAC calculator, as a discriminatory tool produced via federal research funds, is ripe for OCR intervention under the authority granted by Title VI of the Civil Rights Act, 42 USC §2000d et seq because it is state action implemented through individual, health care providers resulting in disparate treatment based on race. Because there is a clear correlation between the VBAC Calculator and race, the anti-discrimination protections of 42 USC 2000d are applicable and ripe for OCR investigation and intervention.

To establish that the VBAC Calculator is having a racially disparate impact we must answer three (3) questions: first, does the adverse effect of the policy or practice fall disproportionately on a race, color, or national origin community? Second, if so, does the evidence establish a substantial, legitimate justification for the policy or practice? Third, is there an alternative policy or practice that would achieve the same legitimate objective but with less discriminatory effect? We assert that the VBAC Calculator, and the policies and practices that stem or affirm its use are not race neutral and lead to a disproportionate impact on Black and Latine/x pregnant and birthing people. And the practice and policies that are used in furtherance of the VBAC Calculator scores lack a substantial, legitimate justification while less discriminatory models exist that center patient's desires, overall health and lead to better health outcomes.

To begin, the Maternal Fetal Medicine University (MFMU) developed a VBAC success calculator to support a person-centered discussion about the risks and benefits of VBACs and ERCD.[167]

Proof of harm or adverse outcomes is required to successfully establish disparate impact liability.[168] Courts have frequently identified Title VI adversity/harm where recipients' policies or practices result in fewer services or benefits, or inferior service or benefits.[169] Title VI bars agencies from "27tilize[ing] criteria or methods of administration which have the effect of subjecting individual to discrimination because of their race, color, or national origin. . ."[170] This may occur where the recipient denies a person from a particular racial group their desired service or benefit. Physical, social, emotional and psychological harms, to name a few, occur for the people who are denied opportunity for autonomous care. Here, harm is quite evident.

Proof of disparity within a protected class that is significantly large enough is also required to successfully establish disparate impact liability.[171] To ensure there is a disparity,

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[167] Nils Chaillet et al., *Validation of a Prediction Model for Vaginal Birth After Cesarean*, 35 J. Obstetrics & Gynaecology Canada 119 (2013).

[168] *E.g.*, Bryan v. Koch, 627 F.2d 612, 617 (2d Cir. 1980); S. Camden Citizens in Action v. N.J. Dep't of Env't. Prot., 145 F. Supp. 2d 446, 487 opinion modified and supplemented, 145 F. Supp. 2d 505 (D.N.J.) (discussing the methods used to "evaluate the 'adversity' of the impact" and considering whether the impacts at issue were "sufficiently adverse" to establish a prima facie case), rev'd on other grounds, 274 F.3d 771 (3d Cir. 2001).

[169] *See* Larry P. v. Riles, 793 F.2d 969, 983 (9th Cir. 1986) (holding that improper placement in special education classes had a "definite adverse effect" because such "classes are dead-end classes which de-emphasize academic skills and stigmatize children improperly placed in them.").

[170] 28 C.F.R. § 42.104(b)(2).

[171] Currently, a Circuit split exists in determining the importance of proving "practical significance" to establish a prima facie case of disparate impact. Recent caselaw establishes a plaintiff's failure to show practical significance does not preclude that plaintiff from instead relying on competent evidence of statistical significance to establish a

OCR would need to evaluate if there is a protected class involved and if statistical evidence exists (or is needed) to support a claim of disparity. A disparity is established if the challenged practice adversely affects a significantly higher proportion of protected class members than non-protected class members.[172]Based upon recent studies and reports that are emerging after more than a decade of using the VBAC calculator, there is a clear and evident racial disparity that results from use of the VBAC Calculator.[173] So even as a facially neutral practice and tool, there is clear evidence that the VBAC success calculator continues to lead to harm for certain groups of people.

Causation between the neutral policy or practice and the harm and disparity is required to successfully establish disparate impact liability. Causation is established where, OCR looks to "statistical evidence of a kind and degree sufficient to show that the practice in question has caused the exclusion of [a particular group] because of their membership in a protected group." [174] Studies and reports reflect that there is a causal link between implementation of the tool and the resulting disparity. Importantly, there is no requirement for an understanding of why the policy results in the disparity merely that it in fact affects people of different races differently and disproportionately. Here, there are direct causal links to the VBAC Calculator and the racial disparity imposed on Black and Latine/x pregnant and birthing people.

Given the circumstances, OCR could reasonably conclude that there is a disparate impact on Black and Latine/x pregnant and birthing people. The next step in the analysis would lead to a fact-specific query as to whether use of the tool serves a legitimate, important and integral purpose and there is no other less discriminatory alternative. Legitimacy may be established where there is proof that a tool is integral to the entity's mission supported by evidence, to avoid speculation.[175] Where, however, a federally funded entity insists on implementing a policy despite its adverse disparate impacts, the investigating agency must scrutinize the recipient's rationale to determine whether the evidence adequately supports it. A violation is established if the investigating agency finds that the evidence does not support the entity's justification, and therefore is not legitimate.[176] "Integral to the mission of the entity" may be established by evaluating the entity, against other like entities but also may take a case-by-case approach. The importance of the justification is evaluated by weighing the reason it was implemented against the harm the policy or practice causes.[177] And generally, the more serious and widespread the

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prima facie case of disparate impact. E.g., compare Jones v. City of Bos., 752 F.3d 38, 53 (1st Cir. 2014) (finding a prima facie disparate impact where there was a 1% difference in selection rates), with Frazier v. Garrison I.S.D., 980 F.2d 1514, 1524 (5th Cir. 1993) (holding that a 4.5% difference in selection rates was trivial).

[172] Tsombanidis v. W. Haven Fire Dep't, 352 F.3d 565, 576–77 (2d Cir. 2003).

[173] Grobman et al., *Development of a Nomogram for Prediction of Vaginal Birth After Cesarean Delivery*, *supra* note 156.

[174] Rose v Wells Fargo & Co., 902 F.2d 1417, 1424 (9th Cir. 1990) (*citing Watson v Forth Worth Bank & Trust*, 487, 977, 944 (1988).

[175] *See e.g.* 24 C.F.R. §§ 100.500(c)(2), 100.500(b)(2); Gashi v. Grubb & Ellis Prop. Mgmt. Servs., Inc., 801 F. Supp. 2d 12, 16 (D. Conn. 2011) (explaining that where the "defendant presents objective evidence to support his assertions, the court is less wary of subjective explanations") (*citing* Soules v. HUD, 967 F.2d 817, 822 (2d Cir. 1992)).

[176] *See* Elston, 997 F. 2d at 1407.

[177] *See* NAACP v. Med. Ctr., Inc., 657 F.2d 1322, 1350 (3d Cir. 1981) (en banc) ("The content of the rebuttal or justification evidence cannot be determined in the abstract. It must be related to the precise impacts suggested by the plaintiffs' evidence."); see also *Gashi*, 801 F. Supp. 2d at 16 (*citing* Huntington, 844 F.2d 929, 937 (2d Cir. 1988), aff'd, 488 U.S. 15 (1988) ("After the defendant presents a legitimate justification, the court must weigh the defendant's justification against the degree of adverse effect shown by the plaintiff.").

adverse disparate impact the practice has caused, the more difficult it is for the entity to assert an acceptable reason for implementation and continuation of the policy or practice.[178] Even then, if the entity is able to establish a legitimate, important goal integral to the mission, the policy or practice also must be connected to the same goal. In this case, even if reducing secondary cesarean surgeries is an acceptable reason for use of this discriminatory tool, the fact that it has the effect of *increasing* secondary cesareans for Black and Latine/x people is reason enough to find this tool's use is illegitimate.

The final step as part of the analysis to establish disparate impact liability hiss a consideration if there are other less discriminatory policies or practices available. Even if the entity establishes a legitimate and important justification that is integral to the mission, there will still be a violation of Title VI if there are less discriminatory policies available that were not used. Here, that is the case. Indeed, informed consent is a less discriminatory policy that was available and not appropriately used. Had legal informed consent been given with regard to the discriminatory nature of the VBAC calculator, that may have overcome its deficiencies.

In their 2010 consensus statement, the NIH recommended that mode-of-birth counseling be "evidence-based, minimize bias, and incorporate a strong emphasis on patient preferences (Cunningham et al., 2010)." Unfortunately, the goals for evidence-based, bias-free, and preference-sensitive mode-of-birth counseling are as yet unfulfilled. A patient-centered approach to discussing the probability for a successful VBAC recognizes that prediction is not a relevant frame for many patients, and therefore, should not play an outsized role in counseling, especially for those patients who are motivated to attempt a VBAC. For those VBAC candidates who desire a numeric estimate of their probability for a successful VBAC, providers should delve into a robust conversation about the multiple hospital, provider, and individual factors that influence successful VBAC. So too, providers should discuss what can be done to potentially increase the probability for success. Pregnant people who have low probabilities for success should be afforded a range of birth options, not just cesarean section. Finally, due to the limitations of VBAC prediction models that use only individual factors, including their limited precision in the lower scores ranges, no VBAC-interested person should be denied a VBAC based on what providers perceive to be a low score. If an obstetrician or other provider does not have the skills to support patients who have (perceived) low probabilities in attempting a VBAC, providers should refer to another obstetrician or a midwife who can help the patient to safely achieve their goals.

3. Modern Day Distribution of Perinatal Services Reflects Structural Racism.

Programs that receive federal funds cannot distinguish among individuals on the basis of race, color or national origin, either directly or indirectly, in the types or quantity in which they provide them.[179] In the agency's own guidance on racial discrimination in healthcare, OCR specifically states that it is a Title VI violation when "a predominantly minority community is provided lower benefits, fewer services, or is subject to harsher rules than a predominantly

[178] *E.g.* Clady v. Cty. of Los Angeles, 770 F.2d 1421, 1432 (9th Cir. 1985) ("As a general principle, the greater the test's adverse impact, the higher the correlation which will be required.").
[179] *See* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).

nonminority community."[180] It is therefore within the scope of OCR's authority to investigate complaints that arise from the inexistence or scarcity of reproductive health services. As of 2014, more than half of rural counties in the U.S. were considered maternity care deserts, with no hospital-based obstetric services.[181] When we carefully examine those maternity deserts we can see that there is a disparate impact based on race, color and national origin.[182] A recent study found that "more than half of rural counties lack obstetric services, and rural counties with more African American and low-income families were less likely to have hospital obstetric services"" Closures of mternal health facilities accelerated during the pandemic.[183]Urban communities are impacted too. When a health system eliminates maternal health services or closes facilities it should be investigated for possible violation of Title VI if the closure or elimination of services will have a disparate impact based on race, color or national origin.

There are particular Title VI concerns that arise in the context of maternity care deserts experienced by Indigenous communities in the United States because of the reality that these communities consistently receive fewer federal resources than other communities. This funding disparity translates into systemic shortages in care access for Indigenous people—including pregnant and birthing people, who sometimes have to travel up to 100 miles to get to a prenatal appointment.[184] A 2018 study found that having to travel 30 miles for hospital-based care led to fewer prenatal visits, which in turn contributed to higher rates of pre-term delivery and negative birth outcomes.[185] While some of this funding disparity may be the result of federal decisions beyond OCR's scope (funding of the Indian Health Service, for example), it is possible that there are also inequities occurring within OCR's jurisdiction since Native Americans are subject to multiple systems with a variety of funding streams. The following section will delve into this further, identifying and analyzing how discriminatory funding policies and other practices lead to unequal (and discriminatory) perinatal healthcare access for Native Americans[186] living in the United States.

B. Native Americans Face Significant Civil Rights Violations in Health Care that OCR Has Authority to Address.

Native Americans residing in the United States have encountered and endured racism, genocide, and human rights violations since European colonists and "explorers" first visited this

[180] Office for Civil Rights, *Civil Rights Requirements Title VI of the Civil Rights Act*, HHS.GOV (Jul. 26, 2013), https://bit.ly/3ni9NCy, *citing* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).
[181] Martha Hostetter & Sarah Klein, *Restoring Access to Maternity Care in Rural America*, THE COMMONWEALTH FUND (Sept. 30, 2021), https://bit.ly/3yhiHqe.
[182] *See* Jamila Taylor *et al.*, *Eliminating Racial Disparities in Maternal and Infant Mortality: A Comprehensive Policy Blueprint*, CTR. FOR AM. PROGRESS (May 2, 2019), https://ampr.gs/3mOI5gw.
[183] Dylan Scott, Maternity wards are shuttering across the US during the pandemic: The closures could make giving birth more dangerous in the United States, Vox, March 7, 2022.
[184] Claire Stremple, *How Far do Alaska Women Have to Go to Give Birth*?, CTR. FOR HEALTH JOURNALISM (Aug. 11, 2020), https://bit.ly/3xN6SYF.
[185] *See* Lynette Hamlin, *Obstetric Access and the Community Health Imperative for Rural Women*, 41 Family & Community Health 105 (2018).
[186] The term "Native American" is used here to include members and descendants of the 574 federally recognized tribes as well as those that self-identify as an Indigenous person to the lands that encompass the United States.

continent.[187] It follows that in the United States, Native Americans also experience race-based discrimination in the context of perinatal health, both in terms of the quality of the care they receive and in the outcomes they experience. After offering some historical context for the discrimination that Native Americans face when seeking healthcare in the United States, this section will provide an overview of how unequal access and lower-quality care amount to unlawful discrimination under Title IV.

1. Native Americans Face Unlawful Discrimination When They Are Granted Unequal Access to Perinatal Services.

The earliest formal relationship between the hundreds of tribes of Native Americans already living on these lands for thousands of years and European colonizers was based on government to government treaties. Though not all tribes successfully negotiated treaties or had them honored when they did, today, there are over 370 ratified treaties between the United States and Native American tribes.[188]

These treaties promise healthcare, education, land, economic opportunity, and other services to Native American people in exchange for the millions of acres of land that was once under their protection.[189] The lack of follow-through on these promises as well as countless federal policies towards Native American tribes have had discriminatory effects on Native American people. These effects could be described as both discrimination on the basis of national origin and race. However, it is essential to recognize that it should not be understood exclusively as race-based discrimination because that conception of discrimination fails to adequately protect Native American sovereignty.

Treaty promises with regards to healthcare have often been accompanied by discriminatory health practices toward Native people.[190] The Indian Health Service hisS)[191] is the health system that was created by the federal government to serve its trust responsibility to provide healthcare for Native American people. This health system has been fraught with chronic underfunding resulting in inadequate health care facilities and a severe shortage of health care professionals that is on its own a form of discrimination.[192]

IHS is often the only Western health care system to which Native people living on rural reservations have access. The crisis of inadequate health services was outlined in a 2003 report by the U.S. Commission on Civil Rights titled "A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country." Eighteen years later, most of the findings in this report remain true. Furthermore, as noted in that report, the "federal government's failure to avail Native Americans of services and programs available to other Americans violates their civil rights."[193]

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[187] U.S. Commission on Civil Rights, *Broken Promises: Continuing Federal Funding Shortfall for Native Americans, Briefing Report* (Sept. 2018), https://bit.ly/39ud4LQ.
[188] National Museum of the American Indian, *Nation to Nation : Treaties Between the United States and the American Indian Nations*, SMITHSONIAN (last accessed June 16, 2022), https://americanindian.si.edu/nationtonation/.
[189] *See* U.S. Commission on Civil Rights, *Broken Promises*, *supra* note 187.
[190] *See* U.S. Commission Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Need in Indian Country*, 1-3, (2003).
[191] Indian Health Services, *Agency Overview* (last accessed June 16, 2022), https://www.ihs.gov/aboutihs/overview/.
[192] *See* U.S. Commission Civil Rights, *A Quiet Crisis*, *supra* note 190, at 4-5.
[193] *See id.*, at 5.

Housed within the Department of Health and Human Services, his IHS has been repeatedly underfunded.[194] Every year, Congress appropriates fuhis to IHS to provide health care services to Indigenous communities throughout the United States.[195] However, according to the National Congress of American Indians, in 2017, the IHS per capita expenditures for patient health services were just $3,332, compared to $9,207 per person for health care spending nationally.[196] In other words, Indigenous communities receive about one third the amount of funding that our healthcare system otherwise deems adequate for covering healthcare costs. Moreover, when Native Americans are unable to access services and programs guaranteed by treaties, they are then vulnerable to civil rights violations in facilities outside of the Indian Health Service.[197]

Discriminatory funding practicehisor the IHS also contributes to poor working conditions for healthcare workers, which in turn leads to lower-quality or non-accessible care,[198] and even obstetric care shut-downs. On September 24th 2021, for example, the labor and delivery unit at Rehoboth-McKinley Christian Hospital closed due to staffing shortages that rendered working conditions at the hospital untenable for employees.[199] On average, staff in the unit deliver between 30 and 40 babies each month, many of whom are members of the nearby Navajo Nation and Zuni Pueblo. Without more people on staff, care providers at Rehoboth-Mckinley could not continue to serve their community. There is only one other hospital in Gallup, and it serves exclusively Native American families. The Rehoboth-McKinley shut-down therefore had a doubly-disproportionate impact on Indigenous birthing people because not only were Rehoboth-McKinley clients left without access, but availability at the other facility—which only serves Native Amer—n families-- was reduced because of increased demand. In August 2020, the Phoenix Indian Medical Center (in the same region, 280 miles away from Gallup) also abruptly closed its obstetrics unit and left many pregnant Native Americans without access to perinatal care.[200] The obstetrics unit at Phoenix Indian Medical Center has not reopened. These shortages are not new. Chronic underfunding of IHS systems has resulted in lack of maternity and obstetric care through IHS facilities for decades. In 2007, the Santa Fe IHS facility closed its obstetrics unit which caused all IHS patients to be referred to outside hospitals for birthing care.[201]

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[194] *See* National Academy of Sciences, Engineering & Medicine, *Appendix A: Native American Health: Historical and Legal Context, in* COMMUNITIES IN ACTION: PATHWAYS TO HEALTH EQUITY (Nat'l Acad. Press, 2017), *citing* Thomas Sequist, *Trends in Quality of Care and Barriers to Improvement in the Indian Health Service*, 26 J. General Int. Med. 480 (May 2011); Donald Warne & Linda Bane Frizzell, *American Indian Health Policy: Historical Trends and Contemporary Issues*, 104 Am. J. Pub. Health S263 (2014).

[195] *See* NASED., *Appendix A: Native American Health: Historical and Legal Context*, *supra* note 194.

[196] National Congress of Am. Indians, *Healthcare: Reducing Disparities in the Federal Healthcare Budget* (2019).

[197] Mary G. Findling, et al., *Discrimination in the United States: Experiences of Native Americans*, 54 (Suppl 2) Health Serv. Rsch. 1431 (2019).

[198] It is worth noting that Native American birthing people with disabilities are doubly discriminated against in this context, experiencing both a general lack of care access because of their status as Native Americans and access barriers stemming from a lack of supportive services that are responsive to the needs of pregnant people with disabilities. *See generally* National Council on Disability, *Parental Disability & Child Welfare in the Native American Community in* Nat'l Council on Disability, *Rocking the Cradle*, *supra* note 67.

[199] *See* Patrick Lohmann, *Gallup Hospital's Birthing Unit to Reopen, but Former Nurse Says Fix Is Just A Band-Aid,* SOURCE NEW MEXICO (Oct. 18, 2021), https://bit.ly/3NWyxvO.

[200] Dalton Walker, *Birthing Center Could Reopen at Pheonix Indian Medical Center*, INDIAN COUNTRY TODAY (Sept. 8, 2021), https://bit.ly/3zE2AEn.

[201] Cynthia Miller, *Nation's First Native Birthing Facility Planned in New Mexico*, THE NEW MEXICAN (Apr. 29, 2018), https://bit.ly/3Oa8EIA.

Many Native people who reside in urban areas utilize IHS as well as public and private health systems. The Urban Indian Health Institute reports that according to U.S. Census data, approximately 71% of American Indians and Alaska Natives live in urban areas.[202] By this data, it would follow that many American Indians and Alaska Natives are seeking health care services and perinatal care in health systems other than IHS, so it is critical to recognize how discriminatory IHS funding, which OCR does not have the power to address, is connected to subsequent discrimination experienced by Native Americans in facilities that OCR can reach. It will be important to ensure that the accountability OCR can provide does not diminish Native Americans' concomitant claim for sovereignty through the honoring of the federal government's treaty obligations.

It is also important to note that in addition to access barriers stemming from a dearth of providers, Native American pregnant people may be reluctant to seek care because of mistrust stemming from historic discrimination at the IHS. A 1976 study published by the US Government Accountability Office found that 3,406 sterilizations were performed on American Indian women without their informed consent between the years of 1973-1976. [203] Prior to this study, an independent study by Dr. Connie Pinkerton-Uri (Choctaw/Cherokee) found that one in four American Indian women had been sterilized without her consent.[204] Dr. Pinkerton-Uri's research indicated that IHS had "singled out full-blooded Indian women for sterilization procedures."[205] Given that these health violations occurred just 45 years ago, and many believe that this type of care from IHS likely continues today, many Native Americans are reluctant to rely on IHS for their healthcare, especially perinatal care.

2. Native Americans Face Unlawful Discrimination When Seeking Perinatal Services.

Unlawful race-based discrimination and structural racism in the provision of perinatal care impact pregnancy and birth outcomes for Native American pregnant people. In addition to the discrimination embedded in policy-making that the government carries out within its federal trust responsibility, Native American people who seek perinatal care in the IHS systems experience race-based discrimination when their providers exhibit bias. This discrimination has been associated with higher rates of infant and maternal mortality and morbidity.[206]

Native American pregnant people encounter race-based bias because the IHS systems do not provide culturally specific and relevant care concerning pregnancy and perinatal care.[207] In some cases, IHS may not provide perinatal care at its local facilities and pregnant people are then referred to neighboring health systems for perinatal care. This process can generate delays and access barriers for people who have difficulty securing transportation to these providers, which in turn compromises the health and well-being of Native American pregnant people.

The institutional policies of the private health systems perpetuate racism. Oftentimes, for example, private health systems designate patients based on race but in the case of Native

[202] Urban Indian Health Institute, *Urban Indian Health* (accessed: June 15, 2022), https://bit.ly/3NRB1vn.
[203] Native Voices, *1976: Government Admits Unauthorized Sterilization of Indian Women*, NAT'L LIBRARY OF MED. (accessed June 15, 2022), https://bit.ly/3xthBX1.
[204] Jane Lawrence, *The Indian Health Service and the Sterilization of Native American Women*, 24 Am. Indian Quarterly 400, 410 (2000).
[205] *Id.* at 411.
[206] National Partnership for Women & Families, *American Indian and Alaska Native Women's Maternal Health: Addressing the Crisis* (2019), https://bit.ly/3n9KxP4.
[207] *Id.*

Americans this may also be occurring due to the complex payment system that results due to referrals from IHS.

(a) By Excluding Traditional Community Birth Practices, Current IHS Policy Fails to Provide Culturally Competent Care.

Title VI applies to intentional discrimination as well as to "procedures, criteria or methods of administration that appear neutral but have a discriminatory effect on individuals because of their race, color, or national origin."[208] This means that a systemic failure to respect or accommodate the birthing traditions of Indigenous birthing people rises to the level of a Title VI violation. Because a history of colonization, forced sterilization and genocide lies at the root of many standard gynecological practices, imposing them ubiquitously is both political and sometimes violent.[209] Although IHS currently allows certified nurse-midwives to provide care through IHS systems, community-based midwifery, births at home on sovereign land, doula, and lactation support are not included in in the IHS maternal health rules .[210] If IHS policy allowed for the provision of perinatal care based on traditional community practices, there would be a more sustainable and cultural specific model of care. By not considering alternative culturally based perinatal care, the IHS' existing policies are racially discriminatory. A failure to train providers in how to administer culturally competent care, as well as a failure to accommodate requests that are based on a cultural belief or norm, has a discriminatory effect on certain communities—namely Indigenous communities and Immigrant communities whose birthing traditions may be less widely recognized or understood by physicians trained in U.S. medical institutions. The HHS website specifically provides that even if there is a nondiscriminatory reason behind a standard practice, it "cannot continue if there are alternatives that would achieve the same objectives but that would exclude fewer minorities."[211] Therefore, so long as a particular request does not jeopardize the overall objective (which presumably is to end labor and delivery with a healthy parent and baby), then policies or practices that fail to accommodate those requests must end.

(b) COVID-19 Has Exacerbated and Created New Avenues for Discrimination Against Native American Pregnant People.

In 2020, the Lovelace Women's Hospital in Albquerque, New Mexico was exposed for one of its discriminatory practices directed at Native American parents and infants.[212] Under the guise of a coronavirus protective measure, the hospital separated newly born Native American

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[208] *See* Office for Civil Rights, *Civil Rights Requirements Title VI of the Civil Rights Act,* HHS.GOV (Jul. 26, 2013), https://bit.ly/3xRrWxm, *citing* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).

[209] Nicolle Gonzales, *Combating "Maternal Health Mysticism" in Native American Communities*, ASPEN INSTIT. (Oct. 17, 2019), https://bit.ly/3MLKp2w.

[210] IND. HEALTH SERV., INDIAN HEALTH MANUAL: NURSE MIDWIFERY § 3-13.4 (2000).

[211] *See* Office for Civil Rights, *Civil Rights Requirements Title VI of the Civil Rights Act,* HHS.GOV (Jul. 26, 2013), https://bit.ly/3QXDDtU, *citing* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).

[212] Bryant Furlow, *A Hospital's Secret Coronavirus Policy Separated Native American Mothers from Their Newborns*, PROPUBLICA (June 13, 2020), https://bit.ly/3HQNRrG.

infants from their birthing parent based on the home ZIP code of the birthing parent.[213] The hospital was utilizing a ZIP code list that identified the particular ZIP codes that are within reservation and Pueblo communities.[214] If a patient identified their home ZIP codes that was on this list, they were subjected to additional COVID virus testing and isolation, resulting in the separation of birthing parent and newly born infant. Investigators determined that this discriminatory practice also violated informed consent because the hospital did not have a formal policy nor did it offer Native American patients the option to decline COVID testing or separation from their babies.[215]

It is critical that OCR utilize its enforcement authority under Section 1557 to process complaints and conduct investigations of individual reports of race-based discrimination, particularly those experienced by Native Americans who utilize IHS facilities and receive referrals from IHS to private health care facilities for perinatal care. Additionally, OCR should consider issuing a report concerning the failures of the IHS regarding perinatal care and its dire impact on Native American maternal and infant mortality and focus on health policy recommendations that might be implemented concerning perinatal care as a federal trust responsibility and a means to address discriminatory practices within IHS systems.

C. Pregnant Immigrants, Refugees and Migrants Face Unequal Treatment in Violation of Title VI.

In addition to providing protection against discrimination on the basis of race and ethnicity, Title VI of the Civil Rights Act prohibits discrimination on the basis of national origin. For pregnant immigrants, refugees, and migrants, obstetric racism and violence including both mistreatment during the perinatal period and barriers to accessing perinatal care is specific form of discrimination according to national origin that is prohibited by Title VI of the Civil Rights Act and section 1557 of the Patient Protection and Affordable Care Act.[216] This section will provide an overview of the prevalence and nature of this discrimination, and argue that OCR has authority to address it.

1. Perinatal Health Disparities Result from Discrimination on the Basis of One's Immigration, Migrant, and Refugee Status.

Discrimination occurs when the national origin of the pregnant person (which encompasses their legal immigration status) creates barriers to accessing perinatal care or influences the way that care is delivered. Pregnant people "experience intersecting forms of discrimination, which have an aggravating negative impact" on health and wellbeing.[217] This is particularly true for pregnant immigrants, refugees, and migrants for whom discrimination based

[213] Bryant Furlow, *A Hospital's Secret Coronavirus Policy Separated Native American Mothers from Their Newborns*, PROPUBLICA (June 13, 2020), https://bit.ly/3HQNRrG..
[214] *Id.*
[215] *Id.; see also* Sandora Tauz TamuPovi, *An Open Letter: Seeking Justice and Systemic Change for Native Families Harmed by Structural Racism*, MEDIUM (Apr. 4, 2020), https://bit.ly/3xOUrM6.
[216] 42 USC § 2000d; 42 USC 18116.
[217] *See* Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3.

on gender, race/ethnicity and socioeconomic status is compounded by vulnerabilities based on national origin, particularly legal status.[218]

Immigration legal status impacts healthcare access, including perinatal care and can be understood as a structural determinant of health.[219] Although immigrants, migrants and refugees are often healthier than the host population on arrival, once in the US they often face "conditions that may exacerbate health and childbearing risks including poverty, social isolation" and discrimination.[220] A growing body of scholarship describes the everyday state controls experienced by immigrants, refugees, and migrants in the US as a form of legal violence that creates systemic structural vulnerabilities with significant impacts on health.[221] Reproductive capacity, in particular, is a locus of specific gendered control over immigrants. Historically, immigrant (cis) women's reproductive capacities have been the basis of specific protections, statuses and restrictions, including differential access to health services and types of visas.[222] Although the provisions of the Affordable Care Act (and related programs) exclude most immigrants, refugees and migrants, a key exception is made for pregnant people. Regardless of national origin, childbirth is considered a medical emergency, triggering extra protections for the pregnant person and unborn fetus.[223] However, on a state level, there is significant variation in the types of health insurance programs available to pregnant immigrants, migrants and refugees. These include emergency Medicaid programs, which often only cover labor and delivery, and the CHIP Unborn Child program, which covers prenatal, labor and delivery, and limited postpartum care.[224] Furthermore, state level variations in immigration policies impact the treatment of immigrants, refugees and migrants such that a similarly situated immigrant could access no-cost prenatal, birth, and postpartum care in one state, and only support during birth in another state and out-of-pocket fees for prenatal and postpartum care.[225] This patchwork of health insurance coverage and immigration policies leads to significant

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[218] Leisy Abrego & Cecilia Menívar, *Immigrant Latina Mothers as Targets of Legal Violence*, 37 Int'l J. of Soc. of the Family 9 (2011).

[219] Meredith Van Natta et al., *Stratified Citizenship, Stratified Health: Examining Latinx Legal Status in the U.S. Healthcare Safety Net*, 220 Soc. Sci. & Med. 49 (2019).

[220] Lisa Merry, Siri Vangen & Rhonda Small, *Caesarean Births Among Migrant Women in High-Income Countries*, 32 Best Practice & Rsch. Clinical Obstetrics & Gynaecology 88 (2016).

[221] *See e.g.* Cecilia Menívar & Leisy Abrego, *Legal Violence: Immigration Law and the Lives of Central American Immigrants*, 117 Am. J. of Soc. 1380 (2012); Abrego & Menívar, *Immigrant Latina Mothers as Targets of Legal Violence*, *supra* note 218.

[222] *See e.g.* Katie Dingeman et al., *Neglected, Protected, Ejected: Latin American women caught by Crimmigration*, 12 Feminist Criminology 293 (2017); Leo R. Chavez, *Anchor Babies and the Challenge of Birthright Citizenship* (Stanford Univ. Press, 2017).

[223] Patricia Zavella, *Contesting Structural Vulnerability through Reproductive Justice Activism with Latina Immigrants in California*, 19 North Am. Dialogue 36–45 (2016) [hereinafter "Zavella, *Contesting Structural Vulnerability"].*; *see also* DHS/HHS/HUD Joint Letter Regarding Immigrant Access to Housing and Services, August 4, 2016; *see also* Section 8 U.S.C. § 1611(b)(l)(A) of the Personal Responsibility and Work Opportunity Act.

[224] Jonathan Drewry et al., *The Impact of the State Children's Health Insurance Program's Unborn Child Ruling Expansions on Foreign-Born Latina Prenatal Care and Birth Outcomes, 2000–2007*, 19 Maternal & Child Health J. 1464 (2015); Danielle Atkins, Mary Held & Lisa Lindley, *The Impact of Expanded Health Insurance Coverage for Unauthorized Pregnant Women on Prenatal Care Utilization*, 35 Pub. Health Nursing 459 (2018); Marian Jarlenski et al., *Insurance Coverage and Prenatal Care Among Low-Income Pregnant Women: An Assessment of States' Adoption of the "Unborn Child" Option in Medicaid and CHIP*, 52 Med. Care 10–19 (2014).

[225] *See e.g.* Kari White et al., *Impact of Alabama's Immigration Law on Access to Health Care Among Latina Immigrants and Children: Implications for National Reform*, 104 Am J Pub. Health 397–405 (2014); .Zavella, *Contesting Structural Vulnerability*, *supra* note 223.

disparities in access to care across the US and treatment during care for pregnant immigrants, migrants and refugees.

Due to the challenges in identifying legal status, most studies on perinatal health treat immigrants, refugees, and migrants as a monolith, which obscures the diversity of experiences across immigrant groups.[226] However, systematic reviews of migrant perinatal health have identified key risk factors and experiences that shape health outcomes for pregnant immigrants, refugees and migrants.[227] These include reduced access to healthcare facilities, poor communication between pregnant immigrants and caregivers; discrimination; and increased incidence of co-morbidities.[228] These coincide with the discrimination described above with regard to maternity care deserts and lack of access to interpretation services and discrimination with regards to national origin which will be discussed further below. Adverse outcomes associated with these discriminatory practices include, "higher incidence of stillbirth and early neonatal death, an increased risk of maternal death, and a higher incidence of postpartum depression."[229]

These experiences of discrimination and the risk factors associated with them vary by national origin and race/ethnicity.[230] While the data doesn't always illustrate that people with worse outcomes also receive less or different services – the data should be a signal to look for conditions where discriminatory practices may be in play, like the VBAC calculator, for example. In some cases, the data doesn't make this clear because the initial inquiry made wrong or inadequate assumptions about the discriminatory context, or was designed to exclude data points that would better illustrate discrimination.[231] Meta analyses indicate that in high income countries such as the US, pregnant immigrants from sub-Saharan Africa and South Asia were disproportionately targeted for emergency and non-emergency caesarean sections compared to the native born population and North African/Middle Eastern and Latine/x pregnant immigrants and it is not clear from the data as collected, how or why these disparities exist.[232] Again, this coincides with the information on the VBAC calculator: Certain groups are given fewer childbirth options because their race, ethnicity or immigration status counts against them in contemporary risk assessment algorithms.[233] Studies have shown that recent immigrants are more likely to report mistreatment during perinatal care and that immigrants of color were twice as likely to report mistreatment compared to their White counterparts.[234]

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[226] Peter Aspinall, *Hidden Needs: Identifying Key Vulnerable Groups in Data Collections: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers*, CTR. FOR HEALTH SERV. STUDIES (2014), https://bit.ly/3QosJNl; Lígia Moreira Almeida et al., *Maternal Healthcare in Migrants: A Systematic Review*, 17 Maternal Child Health J. 1346 (2013).

[227] Anita Gagnon et al., *Migration to Western Industrialised Countries and Perinatal Health: A Systematic Review*, 69 Soc. Sci. & Med. 934 (2009); Almeida et al., *Maternal Healthcare in Migrants*, *supra* note 226.

[228] Almeida et al., *Maternal Healthcare in Migrants*, *supra* note 226.

[229] Almeida et al., *Maternal Healthcare in Migrants*, *supra* note 226.

[230] *See e.g.* Vedam et al., *The Giving Voice to Mothers Study*, *supra* note 10; Elizabeth Howell & Jennifer Zeitlin, *Quality of Care and Disparities in Obstetrics*, 44 Obstetrics & Gynecology Clinics of N. Am. 13 (2017); Almeida et al., *Maternal Healthcare in Migrants*, *supra* note 226; Nicola Heslehurst et al., *Perinatal Health Outcomes and Care Among Asylum Seekers and Refugees: A Systematic Review of Systematic Reviews*, 16 BMC Med. 89 (2018).

[231] Darshali Vyas et al., *Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator*, 29 Women's Health Issues 201 (2019) [hereinafter: "Vyas et al., *Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator*"].

[232] *See* Merry et al., *Cesarean Births Among Migrant Women in High-Income Countries*, *supra* note 220.

[233] Vyas et al., *Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator*, *supra* note 231.

[234] Vedam et al., *The Giving Voice to Mothers Study*, *supra* note 10.

2. Discrimination on the Basis of Immigration, Migrant or Refugee Status is Unlawful and OCR has the Legal Authority to Address It.

Discrimination based on national origin occurs when a pregnant person's national origin limits access to perinatal care or influences the way in which perinatal care is delivered. Given the diversity of the immigrant, refugee, and migrant population, there is a wide range of experiences of discrimination based on national origin, however certain key systemic patterns exist.

Racialization significantly contributes to discrimination based on national origin for pregnant immigrants, refugees, and migrants. Perinatal care is a site of racialization for many pregnant immigrants.[235] One of the dominant themes of contemporary socio-cultural discourses about immigration is the anxiety about pregnant immigrants and the citizenship status of their children. Social theories of "stratified reproduction" describe how reproduction among certain groups is valued and encouraged while among others reproduction is denigrated.[236] Scholars describe how certain groups of immigrants, particularly Asian and Latine/x pregnant people, are constructed as "reproductive threats" based on their race/ethnicity, gender, socioeconomic status and perceived reproductive capacity.[237] These discourses, rooted in specific gender and racial stereotypes, cast certain pregnant immigrants as "unfairly" gaining access to residency and citizenship through the act of reproducing.[238] Immigrant mothers are often compared to mothers on welfare and stigmatized as bad, lazy, fraudulent, and therefore undeserving.[239] These stigmatizing narratives about perceived "anchor babies"[240] and "birth tourism"[241] were codified in recent state department visa policies which now require extra scrutiny of pregnant people.[242]

The US has regularly exerted reproductive control, including sterilization, over groups deemed to be "reproductive threats" in order to "solve" social problems.[243] In California, Latine/x people with childbearing capacity have systematically been disproportionately targeted for sterilization.[244] For immigrant, refugee, and migrant pregnant people, perinatal care becomes a site of "subjectification" where pregnant immigrants are racialized as needy, passive subjects

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[235] Bridges, *Reproducing Race*, *supra* note 32.
[236] Leo Chavez, *A Glass Half Empty: Latina Reproduction and Public Discourse*, 63 Hum. Org. 173 (2005).
[237] Chavez, *Anchor Babies and the Challenge of Birthright Citizenship*, *supra* note 224 ; Leo Chavez, *The Latino Threat: Constructing Immigrants, Citizens, and the Nation* (Stanford Univ. Press, 2013).
[238] Joon Kim, Ernesto Sagás & Karina Cespedes, *Genderacing Immigrant Subjects: 'Anchor Babies' and the Politics of Birthright Citizenship*, 24 Soc. Identities 312 (2018); Sean Wang, *Fetal citizens? Birthright Citizenship, Reproductive Futurism, and the "Panic" over Chinese Birth Tourism in Southern California*, 35 Env't & Planning D: Society and Space 263 (2017).
[239] Tiffany Taylor & Katrina Bloch, *Welfare Queens and Anchor Babies: A Comparative Study of Stigmatized Mothers in the United States*, *in* MOTHERING IN THE AGE OF NEOLIBERALISM, 199–210 (Demeter Press. 2014); Carly Hayden Foster, *Anchor Babies and Welfare Queens: An Essay on Political Rhetoric, Gendered Racism, and Marginalization*, 5 Women, Gender, and Families of Color 50–72 (2017).
[240] Taylor & Bloch, *Welfare Queens and Anchor Babies*, *supra* note 241; Chavez, *Anchor Babies and the Challenge of Birthright Citizenship*, *supra* note 224 ; Chavez, *The Latino Threat*, *supra* note 237.; Kim, Sagás & Cespedes, *Genderacing Immigrant Subject, supra* note 240.
[241] *See* Wang, *Fetal Citizens?*, *supra* note 240.
[242] *See* Visas: Temporary Visitors for Business or Pleasure, 85 FR 4219 (2020).
[243] Chavez, *A Glass Half Empty*, *supra* note 238.
[244] Nicole Novak et al., *Disproportionate Sterilization of Latinos Under California's Eugenic Sterilization Program, 1920–1945*, 108 Am. J. Pub. Health 611 (2018).

requiring state intervention, medicalization and monitoring.[245] In other words, the state tries to control groups whose reproductive capacity and group characteristics are perceived as posing a danger to existing demographic and social structures. The dominant discourse of immigrants as reproductive threats and the implementation of policies specifically focused on immigration and pregnancy contribute to an atmosphere of hostility and uncertainty for pregnant immigrants, refugees, and migrants across the US and leads to discrimination based on national origin. Legitimate mistrust deters pregnant immigrants, refugees and migrants from seeking care, which can lead to less optimal health outcomes. The following examples illustrate some of the most common types of discrimination based on national origin experienced by pregnant immigrants, refugees, and migrants. This is not an exhaustive list but speaks to the larger systemic inequalities.

(a) Discriminatory Administrative Barriers Restrict Access to Care.

One of the most common types of discrimination based on national origin experienced by pregnant immigrants, refugees, and migrants is restricted access to perinatal care stemming from discriminatory gaps in publicly funded insurance programs. Many immigrants rely on state funded perinatal care through programs such as emergency Medicaid programs or the CHIP Unborn Child program which offer limited perinatal care.[246] Emergency Medicaid programs, in particular, often only provide coverage for labor and delivery, thereby excluding pregnant people based on their national origin from prenatal and postpartum care which are critical for healthy outcomes.[247] While the baby- presumed to have U.S. citizen status if born in the U.S.- may benefit from state-funded healthcare after the birth, the person who gave birth to that baby is forgotten and excluded from those benefits based on their national origin.[248] Indeed, for these pregnant people, their national origin dictates both access to perinatal care and the type of perinatal care available. While OCR may not have jurisdiction to address immigration policies, OCR should be alert to the instances when care is denied despite there being state or federal pathways to offering services.

For example, discrimination based on national origin can also cause significant delays in seeking care, even when the pregnant immigrant has a legal right to access care. Low-SES immigrant pregnant people often live in neighborhoods with hyper surveillance from immigration enforcement.[249] Given the climate of hostility towards pregnant immigrants, refugees, and migrants, even if they are aware of their rights to care, many feel intimidated when

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[245] Alyshia Galvez, *Patient Citizens, Immigrant Mothers: Mexican Women, Public Prenatal Care, and the Birth Weight Paradox* (Rutgers Univ. Press, 2011); Bridges, *Reproducing Race*, *supra* note 32.

[246] *See e.g*. Jarlenski et al., *Insurance Coverage and Prenatal Care Among Low-Income Pregnant Women*, *supra* note 224; Jonas J. Swartz et al., *Oregon's Expansion of Prenatal Care Improved Utilization Among Immigrant Women*, 23 Maternal Child Health J. 173 (2019); Nancy, "Berlinger *Getting Creative:" From Workarounds to Sustainable Solutions for Immigrant Health Care*, 47 J. Law Med Ethics 409 (2019).

[247] Maggie Clark, *Medicaid and CHIP Coverage for Pregnant Women: Federal Requirements, State Options*, GEORGETOWN UNIV. CTR. FOR CHILDREN & FAMILIES (2020), https://bit.ly/3MKnbd8; Jarlenski et al., *Insurance Coverage and Prenatal Care Among Low-Income Pregnant Women*, *supra* note 224.

[248] Rachel E. Fabi, Brendan Saloner & Holly Taylor, *State Policymaking and Stated Reasons: Prenatal Care for Undocumented Immigrants in an Era of Abortion Restriction*, 99 The Milbank Quarterly 693 (2021); Casey Colleen Lee, *Unjust Barriers: Prenatal Care and Undocumented Immigrants Comments*, 31 J. Contemp. Health Law & Pol'y 96–119 (2015).

[249] *See e.g.* Zavella, *Contesting Structural Vulnerability*, *supra* note 223; Abrego & Menívar, *Immigrant Latina Mothers as Targets of Legal Violence*, *supra* note 218.

accessing state funded perinatal care because of fears of immigration consequences.[250] OCR has previously identified the fact that immigrant families may be deterred from applying for benefits because of fears about immigration enforcement.[251] OCR has the authority to issue guidance to funding recipients about ways to address- and prevent- healthcare settings participating in immigration enforcement. In doing so, it can eliminate some of the aforementioned barriers and improve access and outcomes for pregnant immigrants, migrants and refugees.

(b) Discriminatory Failures to Ensure Clear Communication Prevent Informed Consent.

Pregnant immigrants, refugees, and migrants also often experience discrimination based on national origin because of communication breakdowns between the pregnant person and provider. Many pregnant immigrants experience language barriers which impede communication and critically hinder effective informed consent.[252] Studies have shown poor communication and caregiver attitudes can cause increased anxieties among pregnant immigrants, particularly during labor and delivery, which can negatively impact outcomes, as discussed above.[253]

Persons with limited English proficiency must be afforded a meaningful opportunity to participate in programs that receive federal funds.[254] However, many birthing people report that they were not provided translation services during childbirth.[255] This is particularly true during the pandemic, when in-person interpreters were categorically deemed "non-essential" and removed from labor and delivery rooms altogether.[256] Studies have linked the lack of translation services to "clinically meaningful and potentially morbid misunderstandings" between providers and birthing people.[257] For example, during the pandemic when no translation was available during childbirth, people with limited English proficiency experienced approximately twice as many pelvic lacerations and significantly higher rates of cesarean delivery.[258]

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[250] White et al., *Impact of Alabama's Immigration Law on Access to Health Care*, *supra* note 227; Zavella, *Contesting Structural Vulnerability*, *supra* note 223; Chavez, *Anchor Babies and the Challenge of Birthright Citizenship*, *supra* note 223 ; Chavez, *The Latino Threat*, *supra* note 237.

[251] Office for Civil Rights, *Department Of Health And Human Services Department Of Agriculture*, HHS.GOV (2008),. https://bit.ly/3NXmfTV

[252] *See e.g*. Almeida et al., *Maternal Healthcare in Migrants*, *supra* note 226; White et al., *Impact of Alabama's Immigration Law on Access to Health Care*, *supra* note 227; Zavella, *Contesting Structural Vulnerability*, *supra* note 223; Merry et al., *Cesarean Births Among Migrant Women in High-Income Countrie*s, *supra* note 220.

[253] Merry et al., *Cesarean Births Among Migrant Women in High-Income Countrie*s, *supra* note 220.

[254] *See* Office for Civil Rights, *Civil Rights Requirements Title VI of the Civil Rights Act*, HHS.GOV (Jul. 26, 2013), https://bit.ly/3QHIXS5, *citing* Prohibition Against Exclusion from Participation in, Denial of Benefits of, and Discrimination Under Federally Assisted Programs on Ground of Race, Color, or National Origin, 42 U.S.C.A. § 2000d (1964).

[255] Ji Youn Seo, Wooksoo Kim & Suzann S. Dickerson, *Korean Immigrant Women's Lived Experience of Childbirth in the United States*, 43 J. of Obstetric, Gynecologic & Neonatal Nursing 305 (2014); Tilly A. Gurman & Davida Becker, *Factors Affecting Latina Immigrants' Perceptions of Maternal Health Care: Findings From a Qualitative Study*, 29 Health Care for Women Int'l 507–526 (2008).

[256] *See* Margot Le Neveu, Zackary Berger & Marielle Gross, *Lost in Translation: The Role of Interpreters on Labor and Delivery*, 4 Health Equity 406 (2020).

[257] *See id.*

[258] *See id.*

Even in normal times, certified interpreters are used for less than 20% of patients who could benefit.[259] Several factors contribute to this—namely, provider preference. Providers cite "time constraints, organizational-level considerations, including interpreter and telephone availability" among factors limiting their interpreter use."[260] This means that patients frequently rely on *ad hoc* interpreters such as family members or staff. Using *ad hoc* or untrained interpreters increases rates of miscommunication through the omission of information, word addition or substitution, and editorialization.[261] This, in turn, denies birthing people with limited English proficiency of their right to a "meaningful opportunity to participate" in their care.

During labor, language barriers can impede the ability of the pregnant person to communicate their preferences, which can cause a low threshold for provider interventions.[262] Studies have shown that greater language fluency is associated with lower risk of caesarean sections.[263] Federal law mandates that providers receiving federal funds make translation services available to people with limited English fluency.[264] However, in practice, translation services and availability vary widely, particularly for less commonly spoken languages.[265] If effective translation services are lacking, providers cannot effectively and safely communicate enough to get full informed consent for interventions. This means that language barriers can result in both increased provider interventions because they are not getting sufficient information from the pregnant person, and that these interventions are non-consensual care. This is a clear example of discrimination based on national origin. This type of discrimination is particularly concerning when considering the statistics of caesarean birth among pregnant immigrants, refugees, and migrants. Therefore, OCR should investigate complaints of obstetric racism and violence that take the form of being denied interpreter services. At the level of the individual patient, not being able to meaningfully participate in one's own care is a significant harm in and of itself- in particular in a hospital context where medical interventions in childbirth are both more common and more invasive than in the context of midwifery care. However, taken as a whole, when a facility systematically fails to provide services that disadvantages some people

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[259] *See* Margot Le Neveu, Zackary Berger & Marielle Gross, *Lost in Translation: The Role of Interpreters on Labor and Delivery*, 4 Health Equity 406 (2020)*, citing* Yael Schenker et al., *Patterns of Interpreter Use for Hospitalized Patients with Limited English Proficiency*, 26 J. Gen. Internal Med. 712 (2011); Amy Tang et al., *From Admission to Discharge: Patterns of Interpreter Use Among Resident Physicians Caring for Hospitalized Patients with Limited English Proficiency*, 25 J. of Health Care for the Poor & Underserved 1784 (2014); Elaine Hsieh, *Not Just "Getting By:" Factors Influencing Providers' Choice of Interpreters*, 30 J. Gen. Internal Med. 75 (2014).

[260] *See* Elaine Hsieh, *Not Just "Getting By:" Factors Influencing Providers' Choice of Interpreters*, 30 J. Gen. Internal Med. 75 (Oct. 2014).

[261] *Id., citing* Glenn Flores, *Errors of Medical Interpretation and their Potential Clinical Consequences: A Comparison of Professional Versus Ad Hoc Versus No Interpreters*, 60 Annals of Emergency Med. 545 (Mar. 2012).

[262] *See e.g.* Merry et al., *Cesarean Births Among Migrant Women in High-Income Countrie*s, *supra* note 220*;* Heslehurst et al., *Perinatal Health Outcomes and Care Among Asylum Seekers and Refugees*, *supra* note 230.

[263] Amy I. Zlot, Debra J. Jackson & Carol Korenbrot, *Association of Acculturation with Cesarean Section Among Latinas*, 9 Maternal Child Health J. 11 (2005).

[264] Title VI of the Civil Rights Act and Section 504 of the Rehab Act of 1973

[265] Caraway L Timmins, *The Impact of Language Barriers on the Health Care of Latinos in the United States: a Review of the Literature and Guidelines for Practice*, 47 J. of Midwifery & Women's Health 80 (2002); Marsha Regenstein & Ellie Andres, *Hospital Language Service Programs: A Closer Look at Translation Practices*, 25 J. of Health Care for the Poor and Underserved 2003 (2014).

while others are advantaged, it is a form of discrimination that OCR must address under its 1557 enforcement obligations.

(c) Provider Bias is Prevalent and Contributes to Discriminatory Mistreatment During Care.

Discrimination based on national origin during the perinatal period can be experienced from a variety of sources- including mistreatment from providers themselves. Changes to immigration policies, including at the state and local level, can significantly affect how pregnant immigrants are treated.[266] After the introduction of more restrictive laws in Alabama, for example, Latine/x pregnant immigrants, who are often racialized as "illegal" regardless of their legal status, reported mistreatment by administrative staff in addition to clinical staff.[267] This discrimination was specifically linked to their national origin.[268] Other types of mistreatment that were routinely experienced by pregnant immigrants during care included being shouted at or scolded, being ignored, and subjected to delays within care delivery.[269] Of course, discrimination based on national origin can be compounded by other forms of discrimination due to the intersectional nature of these issues as discussed above.

Some of the most egregious examples of obstetric racism and violence towards pregnant immigrants concern detention by immigration authorities. Although detention of migrants is not new, under the previous administration the number of immigrants in detention, including pregnant immigrants, increased dramatically.[270] Pregnant migrants were routinely subjected to inhumane conditions, inadequate access to medical care, and unsafe practices including shackling during labor and delivery.[271] Although the Biden administration issued a directive halting the detention of pregnant, postpartum and nursing individuals, the frequency of changes to immigration policies and the lack of oversight within immigration detention centers heighten the risk of these discriminatory policies being restarted.[272] OCR should be open to investigating complaints related to immigration detention in order to ascertain whether it is in fact lawful or a violation of national civil rights laws. The specific vulnerabilities of this population highlight the critical importance of OCR using its power to hold entities to account for discrimination on the basis of national origin.

III. Discrimination on the Basis of Sex Is Widespread Throughout the Perinatal Period and OCR Has the Authority to Address It.

The harm from obstetric violence and other forms of mistreatment in birth is intersectional: in addition to being discriminatory on the basis of race, color, or national origin, it

[266] Fabi, Saloner, and Taylor, *State Policymaking and Stated Reasons, supra* note 248; Berlinger *Getting Creative:" From Workarounds to Sustainable Solutions for Immigrant Health Car*e, *supra* note 246.
[267] White et al., *supra* note 227.
[268] *Id.*
[269] Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10.
[270] Ariella J. Messing, Rachel E. Fabi & Joanne D. Rosen, *Reproductive Injustice at the US Border*, 110 AM. J. PUB. HEALTH 339 (2020); Dana Sussman, *Bound by Injustice: Challenging the Use of Shackles on Incarcerated Pregnant Women*, 15 Cardozo J.L. & Gender 477 (2008).
[271] Messing, Fabi, and Rosen, *State Policymaking and Stated Reasons*, *supra* note 248.
[272] U.S. Immigration & Customs Enforcement, *Directive: Identification and Monitoring of Pregnant, Postpartum, or Nursing Individuals*, ICE.GOV (Jul. 2021), https://bit.ly/3mTqCno.

is compounded by sex-based stereotyping and bias that has been widely recognized by international human rights experts, and which is prohibited under U.S. civil rights protections.

Unfortunately, in the context of perinatal health care, this discrimination is so pervasive as to be normalized. [273] This has historically been the case with other forms of sex-based discrimination and violence, such as intimate partner violence and marital rape, where patriarchal structures obscure and excuse otherwise unjustifiable behavior. The patriarchal structure of obstetrical care, in which OB/GYNs are considered experts to whom pregnant patients owe deference, is a key factor in the discrimination birthing people experience. It is perpetuated by institutional practice and policies that do not actively support self-determination. The inherent imbalance of power has been acknowledged by ACOG, the professional association of OB/GYNs. In a practice bulletin, ACOG's Committee on Ethics affirmed the presence of a "historical imbalance of power in gender relations and in the physician-patient relationship, the constraints on individual choice posed by complex medical technology, and the intersection of gender bias with race and class bias in the attitudes and actions of individuals and institutions."[274]

When such entrenched sex-based discrimination takes place in federally-funded health care facilities, it is a violation of Title IX that OCR has both the legal authority and obligation to address.

A. Mistreatment and Violence During Childbirth are Sex-Based Discrimination that OCR has Legal Authority Under Title IX to Address.

Obstetric racism and violence and other forms of discriminatory mistreatment occur when health care providers or state actors attempt to overmaster the decisions of a birthing person. Such denial of options, coercion, and use of force targets pregnant people for treatment that would be considered unthinkable, and blatantly unlawful, if the patient were not pregnant. Attempts to justify these abuses rely on arguments that pregnancy is exceptional, warranting greater control on the part of the health care provider or the state. These effects are compounded by race as discussed above, but also disability and age which are discussed below. But while pregnancy is the only physiologic condition that results in the birth of a child, it is not the only physiologic condition that warrants complex decision-making. Indeed, the legal standard is that it should be treated like "any other temporary disability."[275] To do otherwise creates a legally subordinate status for people who can become pregnant and relies on notions of acceptable behavior for pregnant patients that categorically excludes trans and gender diverse pregnant people.

1. <u>Subordinating the Rights and Well-Being of a Pregnant Person to the Well-Being of a Fetus Enacts Sex-Based Stereotypes.</u>

[273] *See* Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3.
[274] American College of Obstetricians & Gynecologists, *Committee Opinion No. 439: Informed Consent*, 114 Obstetrics & Gynecology 401 (2009).
[275] "A recipient shall treat pregnancy, childbirth, false pregnancy, termination of pregnancy and recovery therefrom in the same manner and under the same policies as any other temporary disability with respect to any medical or hospital benefit, service, plan or policy which such recipient administers, operates, offers, or participates in." 45 CFR § 86.40(b)(4).

One reason that is often cited for denying pregnant people the same right to make medical decisions as others is concern for fetal well-being. [276] Fetal well-being, directly or indirectly, has been the basis of various forms of now-repudiated sex-based discrimination.[277] Fortunately, modern jurisprudence now recognizes that subordinating people who can become pregnant based on antiquated notions of their proper role as "mothers or mothers-to-be" is impermissible sex-based discrimination.[278] The Equal Protection Clause guarantees that treatment under the law may not be based on gender stereotypes, entrenched perceptions of proper gender roles, or generalizations regarding a person's abilities or characteristics based on gender.[279]

The U.S. Supreme Court recognized in *Price Waterhouse v. Hopkins,* that non-conformity to prescribed gender roles that motivates unfavorable treatment is a form of sex discrimination.[280] Pregnant people who disagree with, decline, or challenge the advice of their health care providers may be perceived as defying the appropriate role of "mothers" as obedient and self-sacrificing. The assertion of bodily autonomy or attempt to protect one's personal safety can be met with coercion or medical abandonment.[281] Harmful consequences to the patient can include retrenchment of paternalism and defensive medical practice, and a failure on the part of health systems, facilities and providers to offer informed choices, particularly around cesarean section surgeries.[282] This framework can be extended to include the experiences of obstetric harm among pregnant transgender people based on the perceived discordance between their gender and the fact of their pregnancy.

2. Sex-Based Stereotypes Underly Mistreatment of Trans and Gender Diverse Patients.

Pregnant people who are transgender or nonbinary also experience discrimination on the basis of sex because of corresponding stereotypes, either that people who have their gender identities (male, intersex, non-binary) cannot or should not be capable of bearing children, or that

[276] Michelle Goodwin, *Fetal Protection Laws: Moral Panic and the New Constitutional Battlefront*, 102 Calif Law Rev. 781 (2014).
[277] *E.g.*, Muller v. Oregon, 208 U.S. 412, 421 (1908) (capping women's work hours in service of "proper discharge of [their] maternal functions"); Bradwell v. State, 83 U.S. 130, 141 (1873) (Bradley, J, concurring) (forbidding women from legal practice due to "duties, complications, and incapacities arising out of the married state").
[278] Nevada Dep't of Human Res. v. Hibbs, 538 US 721, 736 (2003).
[279] *See* United States v. Virginia, 518 U.S. 515 (1996) (invalidating maintenance of single-sex education program); United Auto. Workers v. Johnson Controls, 499 U.S. 187, 205 (1991) (rejecting workplace policies limiting opportunities for female workers based on concern for fertility); Frontiero v. Richardson, 411 U.S. 677 (1973) (holding different qualification criteria for men and women military spousal dependency to heightened scrutiny); Reed v. Reed, 404 U.S. 71 (1971) (rejecting a statute preferring men as between persons equally qualified to administer estates); Cmtys. for Equity v. Mich. High School Athletic Ass'n, 459 F.3d 676 (6th Cir. 2006) (finding subordination of girls' sports in scheduling unconstitutional).
[280] Price Waterhouse v. Hopkins, 490 U.S. 228 (1989)*; see also* Struck v. Secretary of Defense, 460 F.2d 1372 (1971), where the plaintiff, an officer with the U.S. Air Force, was discharged once the Air Force was informed of her pregnancy. Male members of the Air Force who were temporarily unable to serve due to fatherhood were not similarly discharged. Plaintiff argued that her discharge was based on sex-stereotyping — more specifically, her non-conformity with gender stereotypes such as the idea that women who are mothers or expecting mothers should focus on that role exclusively.
[281] Andrew Kotaska, *Informed Consent and Refusal in Obstetrics: A Practical Ethical Guide*, 44 Birth (Mar. 2017).
[282] Heather Cahill, *An Orwellian Scenario: Court Ordered Caesarean Section and Women's Autonomy*, 6 Nursing Ethics 494 (1999).

their bearing children violates norms, morals or customs.[283] When unconscious bias causes the provider to make assumptions that cause them to disrespect their patient's medical decisions, the patient's right to non-discriminatory treatment in healthcare is violated in a way that should be of concern to the OCR. Either way, for birthing women and Trans and Gender Diverse (TGD) people, both the nature of their sex and gender, and the trajectory of pregnancy have been determined in a medical context which is itself rife with race and sex-based stereotypes and discrimination. This creates a particularly insidious form of discrimination when the perpetrators are also the arbiters of medical meaning, which is why a civil rights perspective is so important in securing accountability for these harms. Dimensions of sex-based discrimination will be explored in more detail below.

B. Manifestations of Sex-Based Discrimination in Childbirth that OCR Has the Authority to Address.

Sex-based discrimination manifests in a variety of different ways throughout the perinatal period. This section will provide an overview of some common forms of sex-based discrimination that OCR has the authority to address including forced or coerced procedures, failures to provide gender-affirming care, systemic denials of evidence-based care, sexual assault, and discriminatory application of drug testing and reporting.

1. Forced or Coerced Procedures.

Forced and coerced procedures during childbirth are a form of sex-based discrimination. This form of sex-based discrimination relies on stereotypes that are clearly prohibited by law.[284] These stereotypes and the resulting force, coercion and mistreatment are discriminatory regardless of the gender identity of the pregnant person. While the international community has recognized lack of informed consent as a form of violence against women, OCR has yet to recognize and address this phenomenon in U.S. healthcare, or the ways in which this abuse can also be experienced by TGD pregnant people as a form of discriminatory gender-based violence.

In 2019, the United Nations' Special Rapporteur issued a Report on "a human rights-based approach to mistreatment and violence against women in reproductive health services with a focus on childbirth and obstetric violence."[285] The Report recognized the issue of informed consent as a human right and a safeguard against such violence. Women and TGD birthing people are frequently denied their right to make informed decisions about the healthcare they receive during childbirth and other reproductive health services; this lack of informed consent

[283] Samira Seraji. *Reproduction and Gender Self-Determination: Fertile Grounds for Trans Legal Advocacy*. 28.2 Michigan J. of Gender & Law 251, 267-275 (2022) (exploring whether the medical industry's apathy towards TGD reproductive choices stems from a misguided belief that TGD people do not desire to keep their reproductive capacities or whether it reflects an overall belief that TGD people should not reproduce based on assumptions that TGD people will be incompetent parents or will threaten conventional standards of sex and sexuality. Taking both possibilities into consideration, it is evident that the bottom line is that TGD people's reproductive wishes and potentials are severely impacted by pervading myths about their desire to reproduce and the state's interest in limiting their reproductive capacity).

[284] 42 USC 18116(a); 20 USC 1681 *et seq*; Price Waterhouse v. Hopkins, 490 U.S. 228 (1989); United States v. Virginia, United Auto. Workers v. Johnson Controls, Frontiero v. Richardson, Reed v. Reed, Cmtys. for Equity v. Mich. High School Athletic Ass'n.

[285] Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3.

constitutes a human rights violation that could be attributed to States and national health systems."[286] The OCR is uniquely positioned to address the systemic violation of informed consent in childbirth as a form of sex-based discrimination. This should include but not be limited to accountability for lack of informed consent's most violent manifestation: the use of coercion, threats, and force to impose surgeries and other interventions on birthing people which has been described above in the context of race-based discrimination but bears repeating here as a form of sex-based discrimination.

Violation of birthing patients' rights to informed consent and refusal is a common form of sex-based discrimination during childbirth. One premise for these violations is the medical providers wrongly standing-in as decision-makers for the fetus and also wrongly "balancing" the interests of the fetus against the interests of the birthing person.[287] This decision-making posture is discriminatory.

Although the universal bioethical duty of informed consent is enshrined as the law of informed consent in every state, and jurisprudence on the patient's rights to medical decision-making is recognized in the federal Constitutional due process right to physical autonomy, see *Cruzan*, supra, the violation of this right in the context of pregnancy is widespread. Surveys of American birthing people regarding their experiences of obstetric care indicate that the violation of informed consent is widespread in obstetric healthcare, especially for people of color and other marginalized groups, but that access to legal redress for physical and psychological injuries caused by these violations is insecure.

In 2014, non-profit Human Rights in Childbirth filed an *amicus curiae* brief in the case of *Rinat Dray v. Staten Island Memorial Hospital (also discussed above)*, which includes an appendix of 44 first-person narratives of patients reporting lasting post-partum traumas a result of informed consent violations in U.S. obstetric care.[288] The *amicus* brief draws from these voices to present additional evidence and argument that the coercion, threats, and force experienced by Rinat Dray are widespread, and that many patients experiencing similar abuses were relying on the court to uphold the right to informed consent during childbirth. OCR could significantly impact and reduce the incidence of obstetric racism and violence, including the use of coercion, threats, and force toward patients to ensure their compliance with medical recommendations, by recognizing that birthing people have the same right to medical decision-making as every other patient, and that the violation of the patient's right to informed consent on the basis of the patient's pregnancy is discrimination on the basis of sex that fits within OCR's Title IX enforcement authority.

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[286] Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3 at 7.

[287] Elselijin Kingma, *Harming One to Benefit Another: The Paradox of Autonomy and Consent in Maternity Care*, 35 Bioethics 456 (Jun. 2021); Center for Reproductive Rights, *Whose Right to Life? Women's Rights and Prenatal Protections Under Human Rights and Comparative Law* (2012); *See also* United Nations Human Rights Special Working Group on the Issue of Discrimination Against Women in Law and Practice, *Women's Autonomy, Equality and Reproductive Health in International Human Rights: Between Recognition, Backlash and Regressive Trends*, at 2 (Oct. 2017) ("In the current discourse, the necessity of putting women's human rights at the center of the policy considerations regarding termination of their pregnancy is obfuscated by the rhetoric and political power behind the argument that there is a symmetrical balance of rights to life of two entities: the woman and the unborn. But there is no such contestation in international human rights law. It was well settled in the 1949 UDHR and upheld in the ICCPR that the human rights accorded under IHRL are accorded to those who have been born."); *See also* Jamie R. Abrams, *Distorted and Diminished Tort Claims for Women*, 34 Cardozo L. Rev. 1955, 1975 *et seq.* (2012).

[288] Brief for Human Rights in Childbirth et al. as Amici Curiae Supporting Plaintiff Rinat Dray, Rinat Dray v. Staten Island Univ. Hospital et al., 2021 WL 485645 (2014) (No. 500510/14).

The need for action by the OCR is underscored by the fact that professional organizations like the American College of Obstetrics and Gynecology (ACOG) have been unable to end the violation of birthing patients' rights by clarifying those rights for medical providers. ACOG's Ethics Committee has repeatedly recognized that pregnant patients retain the right of informed consent and refusal, even if the provider perceives the fetus to be endangered by the patient's decision.[289] Patient reports of informed consent violations during childbirth indicate that the bioethical and legal duty of informed consent is violated not only by providers, but also by hospitals that mandate surgical delivery at the policy level (for pregnant patients with, for example, prior cesarean sections, regardless of the patients' consent to surgery).[290] When patients are subjected to mandated surgery, or to coercion, threats and force on the basis of the provider's claim of concern for the fetus, the patient's fundamental constitutional right to autonomy is violated on the basis of their reproductive status, both as a form of discrimination based on sex and based on pregnancy.

Informed consent and refusal mandates respectful, individualized care through the process of conversation between provider and patient about the patient's clinical condition, the risks and benefits of their alternatives for treatment, and support for the patient's informed medical decision to accept or decline a recommended treatment.[291] Because no authoritative federal body like the OCR has declared that the right to informed consent may not be violated on the basis of the patient's pregnancy, the violation of that right has become normalized. The violation of that right has become normalized in obstetrics and will remain so until an authoritative federal body makes clear that the right of informed consent is retained by pregnant patients.[292]

2. Failure to Provide Gender-Affirming Pregnancy-Related Care

Pregnant transgender people experience sex-based discrimination across all forms of healthcare, including obstetric care. Transgender people experience obstetric harms, including medically-unjustifiable refusals of care[293] "on the basis of sex," and their experience in obstetric care is ripe for OCR intervention under the authority granted by Section 1557.

Our healthcare system systematically fails TGD people. Upon mere contact, healthcare providers, either inadvertently or intentionally, tag TGD people as ineligible for respect and care. A routine physical examination can result in uncomfortable interpersonal conflicts or ignorance and/or disdain with serious medical consequences. For example, TGD people report that one of the most significant barriers in access to care is provider ignorance about sex and gender.[294] Harmful practices can include using a patient's deadname (i.e. the name they were given at birth

[289] American College of Obstetricians & Gynecologists, *Committee Opinion No. 664: Refusal of Medically Recommended Treatment During Pregnancy* (2016).
[290] Bridget Basile Ibrahim et al., "*I Had to Fight for My VBAC": A Mixed Methods Exploration of Women's Experiences of Pregnancy and Vaginal Birth after Cesarean in the United States*, 48 Birth 164 (2021); International Cesarean Awareness Network, *VBAC Ban Database Initiative*, https://bit.ly/3beS8ca (accessed Jun. 24, 2022); Christina Pascucci, *VBAC Bans: The Insanity of Mandatory Surgery*, IMPROVING BIRTH (Apr. 14, 2014), https://bit.ly/3Omv6Pt.
[291] *See* discussion of the doctrine of informed consent *supra* note 23.
[292] *See* discussion of the doctrine of informed consent *supra* note 23..
[293] S.E. James et al., *Executive Summary of the Report of the 2015 U.S. Transgender Survey*, NAT'L CTR. FOR TRANSGENDER EQUAL. (2016), https://bit.ly/3OfhLrF.
[294] Joshua D. Safer, et al., *Barriers to Health Care for Transgender Individuals*, 23 Current Opinions in Endocrinology & Diabetes & Obesity 168 (2015).

that was aligned with their sex assigned at birth), using incorrect pronouns, invasive questions about one's primary and secondary sex characteristics, and outright refusal.[295] Respondents to a 2015 survey reported high levels of mistreatment when seeking health care.[296] This mistreatment produces a reality in which nearly one-quarter of respondents reported that they did not seek the health care at all in the year prior to completing the survey due to fear of being mistreated as a transgender person.[297]

During pregnancy and childbirth the impact of this harm is even more pronounced because of the highly gendered ways in which our culture portrays pregnancy, and the assumption on the part of most providers (and laws) that only cisgender women become pregnant. Transgender lawyer and activist Chase Strangio, who is a transgender man, describes the distressing impact of this assumption when recounting an experience he had with his gynecologist.[298] After suffering from severe pelvic pain for months, Strangio scheduled a gynecologist appointment. Upon laying eyes upon Strangio, the doctor said, "I assume you're here about a hysterectomy"—a major surgery that would end his ability to carry a child.[299] The gynecologist made this assumption, without knowing anything about Strangio's relationship to his body and gender identity, based on an incorrect notion that trans men do not birth babies.

But trans people, like others, may value having children that are genetically related to them. The first major clinical study on reproductive desire in trans men found that the majority of trans men surveyed *do* wish to preserve their fertility, have biological children, and establish a family in the future.[300] A 2002 online survey measuring reproductive desire in European trans women showed similar results.[301] Healthcare providers should not assume that trans people want to rid themselves of their reproductive capacities. Indeed, healthcare providers should *listen* to their trans patients and provide them with care in accordance with their individual reproductive desires.[302] This listening should occur in the aggregate as well: the prevalence of mistreatment in the health care system more broadly speaks to a need for more research into the experiences of TGD people during the perinatal period.

OCR has the authority to issue guidance to federally funded healthcare providers, as well as information to patients about their rights to be free from discrimination. Issuing specific guidance and information surrounding the reproductive rights of transgender patients is within the scope of OCR's capabilities. The Agency can- and should- provide these resources as well as investigate individual complaints of discrimination on the basis of one's TGD identity.

3. Systemic Denial of Evidence-Based Care

Compounding the lack of informed consent and refusal is the fact that health systems, facilities and providers largely deny pregnant people access to evidence-based care. Worse,

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[295] S.E. James et al., *Executive Summary of the Report of the 2015 U.S. Transgender Survey*, *supra* note 293.
[296] *See id.*
[297] *See id.*
[298] Chase Strangio, *Can Reproductive Trans Bodies Exist?*, 19 CUNY L. Rev. 223 (2016).
[299] *Id*.
[300] Katrien Wierckx, et al., *Reproductive Wish in Transsexual Men*, 27 Hum. Reprod. 483, 486 (2012).
[301] Julian Honkasalo, *In the Shadow of Eugenics: Transgender Sterilization and the Struggle for Self-Determination, in* THE EMERGENCE OF TRANS: CULTURES, POLITICS, AND EVERYDAY LIVES, 17, 26-7 (Ruth Pearce et al. eds., 2020).
[302] *See* Laura Nixon, *The Right to (Trans) Parent: A Reproductive Justice Approach to Reproductive Rights, Fertility, and Family-Building Issues Facing Transgender People*, 20 Wm. & Mary J. Women & L. 73, 93 (2013).

while the sources of care for most pregnant people in the United States are deficient in evidence basis, care that *is* evidence-based is much less accessible. Although U.S. law has historically offered patients no civil right of access to health care (outside of employment law), much less to a certain *kind* of care, the Affordable Care Act's amendment of Title VI of the Civil Rights Act to forbid discrimination in health programs and activities receiving federal financial assistance[303] suggests that broader interpretations of discrimination are warranted. The systemic failure to assure access to evidence-based care is a form of sex-based discrimination: care that is designed for people with childbearing capacity is marred with uniquely egregious acceptance of, and systemic support for, care options and practices that are non-evidence based.[304] Other healthcare fields, ones not specifically designed to treat people with childbearing capacity, do not promote non-evidence-based care protocols to the same extent or penalize care options that are evidence-based. This difference is rooted in medical paternalism that promotes medical intervention and replaces patient decision-making with the decisions of providers, facilities or the state.

(a) Non-Evidence-Based Care Practices Are More Prevalent in the Context of Pregnancy and Childbirth Than in Other Healthcare Contexts

The American College of Obstetricians and Gynecologists (ACOG) admitted in 2011 that most obstetric care is not evidence-based, when it revealed that only one-third of its published recommendations for clinical practice were based on "good and consistent scientific evidence."[305] In 2012, when Childbirth Connection initiated a "long-term program to promote evidence-based maternity care through policy and quality initiatives,"[306] it found:

- Unwarranted practice variation is widespread across geographic areas, facilities, and clinicians in maternity care;
- Pervasive gaps between evidence and practice reflect both overuse of unwarranted practices and underuse of beneficial practices in maternity care;
- Clinical guidelines do not reliably reflect the most valid scientific evidence. […].[307]

These shortcomings were judged all the more concerning due to maternity care's head start in the 1970s in developing reviews of best evidence.[308] It is in the investigation of individual practices, however, that the harmful effects of non-evidence-based care become apparent and make the case for extending the authority of the Office for Civil Rights to accept discrimination claims on that basis.

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[303] 42 U.S.C. § 18116.
[304] Aron C. Sousa & Alice Dreger, *The Difference Between Science and Technology in Birth*, 15 Virtual Mentor 786 (2013).
[305] Jason D. Wright, *et al*., *Scientific Evidence Underlying the American College of Obstetricians and Gynecologists' Practice Bulletins*, 118 Obstetrics & Gynecology 505 (2011).
[306] Childbirth Connection, *History* (last visited November 18, 2021), https://bit.ly/38th8LS.
[307] Carol Sakala, et al., *Maternity Care and Liability: Most Promising Policy Strategies for Improvement*, 23 Women's Health Issues e25, e30 (2013).
[308] *Id.*

Consider the example of Vaginal Birth After Cesarean (VBAC), whose occurrence in the United States (13.3% as of 2018) [309] is low by any standards. U.S. Healthy People established a goal to increase VBAC to 18.3% by 2020, but although 2020 data are not yet available, trends suggest that the goal will not be reached.[310] Yet the VBAC rate in certain other countries ranged from 44-55% in 2016.[311] In spite of ample evidence that planned VBAC is a safe option for most birthing people with a previous cesarean delivery,[312] the low U.S. rate suggests VBAC is generally inaccessible and contributes considerably to the U.S. overall cesarean surgery rate through repeat cesarean surgery. In other words, health systems, facilities and providers divert thousands of pregnant people from safe and achievable VBACs into surgeries that carry at least double the risk of maternal mortality and severe maternal morbidity.[313] Thus, the insistence on a non-evidence-based intervention leads directly to increased maternal morbidity and mortality.

This pattern repeats in other common maternity care practices. Overwhelming use of continuous fetal heart monitoring, with its 99% false positive rate (a rate far worse than chance), also increases cesarean surgeries.[314] The persistence of episiotomy, for which evidence does not support routine use,[315] and its highly variable use between providers, suggests it is deployed for provider and facility convenience, "to accelerate labor or manage clinical capacity strain, particularly in hospitals with high-delivery volume…"[316] The performance of multiple vaginal exams on pregnant people in labor in order to determine cervical dilation is "without good evidence of effectiveness,"[317] yet remains the norm. Beyond a lack of effectiveness, such exams are widely acknowledged to raise the risk of infection[318] and, moreover, are experienced by some birthing people as sexual trauma (*see* section III.B.4.).[319]

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[309] Michelle J.K. Osterman, *Recent trends in Vaginal Birth After Cesarean Delivery: United States, 2016–2018*, 359 NCHS Data Brief 1 (2020).
[310] *Id.* at 5.
[311] Ingela Lundgren, *et al., Clinicians' Views of Factors of Importance for Improving the Rate of VBAC (Vaginal Birth after Caesarean Section): A Study from Countries with Low VBAC Rates*, 16 BMC Pregnancy & Childbirth 1, 2 (2016).
[312] *Id.*
[313] José Villar, et al., *Maternal and Neonatal Individual Risks and Benefits Associated with Caesarean Delivery: Multicentre Prospective Study*, 335 BMJ: British Med. J. 1, 4 (2007); Janet Currie & W. Bentley MacLeod, *First Do No Harm? Tort Reforms and Birth Outcomes*, 123 Quarterly J. Econ. 795 (2008); David Dranove & Yasutora Watanabe, *Influence and Deterrence: How Obstetricians Respond to Litigation against Themselves and their Colleagues*, 12 Am. L. & Econ. Review 69 (2010); Lisa Dubay et al., *The Impact of Malpractice Fears on Cesarean Section Rates*, 18 J. Health Econ. 491 (1999).
[314] Thomas P. Sartwelle, et al., *Cerebral Palsy, Cesarean Sections, and Electronic Fetal Monitoring: All the Light We Cannot See*, 14 Clinical Ethics 107, 110 (2019).
[315] Evidence does not support maternal benefits traditionally ascribed to routine episiotomy. Katherine Hartmann, et al., *Outcomes of Routine Episiotomy: A Systematic Review*, 293 JAMA 2141, 2141 (2005).
[316] Ava D. Mandelbaum, et al., *National Trends in Utilization of Episiotomy and Factors Associated with High-Utilization Centers in the United States*, 4 J. Women's Health & Dev. 82, 91 (2021).
[317] Soo Downe, *et al*., *Routine Vaginal Examinations for Assessing Progress of Labour to Improve Outcomes for Women and Babies at Term*, 7 Cochrane Database of Systematic Rev. 1, 2 (2013).
[318] Usha Christopher, et al., *Multiple Vaginal Examinations and Early Neonatal Sepsis*, 8 Int'l J. of Reprod., Contraception, Obstetrics & Gynecology 876 (2019).
[319] Stephanie Tillman, *Protecting our Patients from Sexual Assault*, 56 J. of Psychosocial Nursing & Mental Health Serv. 2 (2018); Stephanie Tillman, *Protecting Our Patients from Sexual Assault*, 56 J. of Psychosoc. Nursing & Mental Health 2 (2018); *see also* discussion *infra* Section III.B.4.

These are only a few of the non-evidence-based practices that health systems, facilities and providers have normalized in the U.S. maternity care system. Differential use of interventions happen for complex reasons, including financial incentives.[320] Providers report that malpractice liability is a factor in these differences but research does not support this perception.[321] Research does indicate, however, that overuse of certain non-evidence-based interventions is correlated with policies that value the health and rights of the fetus over those of the pregnant person.[322]

Earlier sections illustrate, though not exhaustively, how this system came about through concerted policy choices rooted in racism and sexism.[323] That these practices have been mainstreamed speaks to widespread acceptance of substandard care given to childbearing people. This acceptance is rooted in a long history of biomedical paternalism fundamentally geared toward provider control over childbirth and its associated risks rather than toward the interests, autonomy and well-being of pregnant people.

The next section argues that the legal and payor barriers that obstruct access to midwives and doulas are also a form of sex-based discrimination.

(b) Evidence-Based, Patient-Centered Care Practices Are Systemically Unsupported - And In Some Instances, Actively Marginalized or Criminalized Through Existing Legal and Insurance Frameworks.

Fortunately, evidence-based models of care are in operation – and birthing people are clamoring for access to them.[324] The use of midwives, community birth, doulas, and lactation support all have been shown to improve both outcomes and patient satisfaction.[325] However, these forms of care are often systemically unsupported. In fact, these care providers are also discriminated against because of their status in a protected class. This section will provide an overview of different forms of evidence-based models of care that are marginalized and sometimes actively criminalized by existing legal frameworks.

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[320] Rie Sakai-Bizmark et. al., *Evaluation of Hospital Cesarean Delivery-Related Profits and Rates in the United States*, 4(3) JAMA Network Open e212235 (2021).
[321] José Villar, et al., *Maternal and Neonatal Individual Risks and Benefits Associated with Caesarean Delivery: Multicentre Prospective Study*, 335 British Med. J. 1, 4 (2007); Janet Currie & W. Bentley MacLeod, *First Do No Harm? Tort Reforms and Birth Outcomes*, 123 Quarterly J. Econ. 795 (2008); David Dranove & Yasutora Watanabe, *Influence and Deterrence: How Obstetricians Respond to Litigation against Themselves and their Colleagues*, 12 Am. L. & Econ. Review 69 (2010); Lisa Dubay et al., *The Impact of Malpractice Fears on Cesarean Section Rates*, 18 J. Health Econ. 491 (1999).
[322] *See id.; see also* Louise Roth, The Business of Birth (NYU Press, 2021); *see also* discussion *infra* III.A.1.
[323] *See* discussion *infra* Sections I.A, II.A.
[324] Eugene R. Declercq, et al., *Major Survey findings of Listening to Mothers^{SM} III: new mothers speak out*, 23 J. Perinatal Educ. 17, 21 (2014).
[325] Carol Sakala, et al., *Improving our Maternity Care Now*, NAT'L PARTNERSHIP FOR WOMEN & FAMILIES, at 84 (Sept. 2020). https://bit.ly/3HU5tTz.

(1) Midwifery Care and Community Birth.

Midwives are maternity care providers who practice according to the Midwife Model of Care,[326] a model that emphasizes physiologic birth and prevention rather than intervention. Midwives provide superior outcomes[327] at a greatly reduced cost.[328] In the face of the graying of the obstetrics profession,[329] its members' unwillingness to locate in rural areas,[330] the extraordinarily high cost of conventional maternity care, and the subpar maternal and neonatal outcomes produced by that system, one would expect greater uptake of midwifery care. Far from integrating midwifery, however, state governments, prodded by newly organized physicians, began attempts in the early twentieth century to dismantle the profession, often based on explicitly sexist, xenophobic, colonialist, and racist grounds.[331]

> Private and academic physicians publicly attacked the reputations of midwives as a group, characterizing them as being poor, black, immigrants, dirty, illiterate, untrained, ignorant, immoral, drunken, unprincipled, overconfident, superstitious, callous, rough, 'relics of barbarism' and in some cases criminal abortionists.[332]

Thus, obstetrics obtained its status as the dominant model of care in the United States arguably through unlawful discrimination. The explicit discrimination of the time has given way to a more obscured but equally persistent version.

During midwifery's resurgence in the past fifty years,[333] it has hardly been welcomed with open arms. State administrators, insurance plans, medical providers and institutions all work to undermine midwives of both national credentials (Certified Nurse-Midwives and Certified Professional Midwives) through a variety of tactics. Educated, trained, certified, and licensed midwives struggle to obtain the right to independent practice and prescriptive authority. Many midwives are bound by physician supervision requirements, whether by state law or by hospital policy. Professional midwives are not licensed to practice at all in some states;[334] some states pursue criminal charges instead of, or in the context of, restrictive regulation;[335] and punishment for accessing midwifery care is levied against families as well as midwives when they seek to

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[326] Midwives Alliance of North America, *The Midwives Model of Care* (2010), https://bit.ly/3wg9pK9.
[327] Andrea Nove, et al. *Potential Impact of Midwives in Preventing and Reducing Maternal and Neonatal Mortality and Stillbirths: A Lives Saved Tool Modelling Study*, 9 Lancet Global Health e24 (2021).
[328] David A. Anderson & Gabrielle M. Gilkison, *The Cost of Home Birth in the United States*, 18 Int'l J. of Envtl. Rsch, & Pub. Health 10361 (2021).
[329] Jaime Rosenberg, *Physician Shortage Likely to Impact OB/GYN Workforce in Coming Years*, AM. J. MANAGED CARE (Sept. 21, 2019) https://bit.ly/3LsfQyk.
[330] *Id.*
[331] Leslie J. Reagan, *When Abortion Was a Crime: Women, Medicine, and Law in the United States, 1867-1973* (1997).
[332] Judith Pence Rooks, *Midwifery and Childbirth in America* 25 (1997).
[333] Lisa L. Chalidze, *Misinformed Consent: Non-Medical Bases for American Birth Recommendations as a Human Rights Issue*, 54 N.Y.L. Sch. L. Rev. 59, 70-71 (2009).
[334] The Big Push for Midwives Campaign, *Pushstates in Action*, https://bit.ly/3LjcFJa (last visited Feb. 7, 2022).
[335] Jennifer Block, *The Criminalization of the American Midwife*, Longreads, March 2020.

transfer from home or birth center care.[336] In states that offer midwife licensing, some do so under boards of nursing, medicine, or larger public health departments, thus establishing midwives as a minority presence in their own regulation. These practices all fall under the umbrella of anti-competitive behavior, yet midwives' ability to mount antitrust actions or, indeed, lawsuits of any kind is limited by a profession that is not associated with large institutions, in-house counsel, or substantial personal income.

While these practices prevent midwives from working to the full extent of their education and skills, pregnant people's access to midwifery care is also compromised by discrimination in insurance coverage, particularly for births that take place in homes and birth centers, *i.e.* community birth. While hospital-based nurse-midwives are typically included in insurance plans, professional midwives and other midwives who attend community births face unreliable and highly variable inclusion in private insurance plans despite state ACA-required benchmark plans that establish which services must be included as "essential health benefits."[337] The problem is far worse under public insurance plans; only a handful of states extend Medicaid coverage, which funds approximately half of U.S. births, to community birth.[338] State Medicaid agencies have the power to extend coverage to midwives and community birth, but often refuse to do so.[339] State maternal-infant health improvement efforts, or those directly funded by DHS, often neglect to include midwives, depending only on representatives of obstetrics to set the course for change.

(2) Doulas and Lactation Consultants.

Advocates, particularly advocates of Color, are demanding access not only to community midwifery, but also to doula care. A doula is not a health care provider, but rather a pregnancy, labor, and postpartum coach who supports clients in achieving their defined goals, most notably during labor and delivery. The effectiveness of doula care is so pronounced[340] that according to pediatrician and researcher John Kennell, "If a doula were a drug, it would be malpractice not to use it."[341]

Doulas are less subject than midwives are to opposition by organized medicine; their role as support personnel can often be perceived as extending the work of overtaxed Labor and

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[336] Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10.
[337] Note that some states explicitly *exclude* mandated coverage, as is the case in Michigan, that excludes mandates for coverage of birth centers and home births. *See* Colin Seeerger, *State Benchmark Health Insurance Plans Fall Short in Advancing Maternal Health*, CTR. FOR AM. PROGRESS (Apr. 30, 2021), https://ampr.gs/3zEPjvf.
[338] This source claims that 18 states extend Medicaid coverage to CPMs, but a closer examination of the particulars reveal limiting factors that suggest the actual count is far lower. The National Academy for State Health Policy, *Midwife Medicaid Reimbursement Policies by State*, NASHP.ORG (Apr. 15, 2022), https://bit.ly/39rEr8W.
[339] Tara Law, *Home Births Became More Popular During the Pandemic. But Many Insurers Still Don't Cover Them.*, TIME (Feb. 11, 2022). https://bit.ly/3A5aU07.
[340] Katy B. Kozhimannil, et al., *Modeling the Cost-Effectiveness of Doula Care Associated with Reductions in Preterm Birth and Cesarean Delivery*, 43 Birth 20 (2016).
[341] Lisa Campo-Engelstein & Paul Burcher, *Reproductive Ethics II: New Ideas and Innovations* (2018).

Delivery nurses.[342] Yet doulas' position as employees of the birthing person rather than of the hospital can bring them into disputes with hospital personnel. "Doulas must constantly serve as a bridge between the sometimes conflicting desires of birthing women and the protocols of the medical system …"[343]

Pregnant people's access to doulas is limited by similar factors listed above for midwives: Private insurance rarely covers doula care.[344] Several states have moved forward with plans to extend Medicaid coverage to doulas; while this is a promising development, it does not resolve the inherent conflicts mentioned above, which can lead to health systems, facilities or providers ejecting or banning doulas from hospitals, leaving doulas with little recourse but to seek adjudication within the state Medicaid agency or its contracted Managed Care Organizations through which doulas are assigned to clients. It is easy to imagine how such institutions might favor the interests of a massive health care system against those of an independent contractor doula. It follows, then, that the very reasons doulas are needed to promote better births are the same ones that threaten their ability to act within the larger medical system – which in turn further reduces access to their services.

4. Sexual Assault or Invasive Procedures Compounding Sexual Assault

Sex-based discrimination manifests in forced and coerced procedures, failure to provide gender-affirming pregnancy-related care, systemic denial of evidence-based care, and through overt sexual assault and invasive procedures compounding sexual assault. Below are examples of sexual assault in the course of obstetric care, as well as examples of procedures that compound sexual assault. OCR has enforcement authority over sex discrimination in healthcare, which encompasses discrimination based on pregnancy status as well as sexual harassment including sexual assault.[345]

(a) Sexual Assault by a Healthcare Provider in the Course of Obstetric Care Constitutes Discrimination under OCR's Title IX Enforcement Authority.

Under 20 USC §1092, sexual assault is defined by reference to the Federal Bureau of Investigation's National Incident-Based Reporting System (NIBRS), and includes sexual assault with an object, defined as:

> To use an object or instrument to unlawfully penetrate, however slightly, the genital or anal opening of the body of another person, forcibly and/or

[342] Lois Eve Ballen & Ann J. Fulcher, *Nurses and Doulas: Complementary Roles to Provide Optimal Maternity Care*, 35 J. of Obstetric, Gynecologic, & Neonatal Nursing 304, 305 (2006).
[343] Monica Reese Basile, *Reproductive Justice and Childbirth Reform: Doulas as Agents of Social Change*, PhD diss., Univ. of Iowa, 2012.
[344] Nan Strauss, Carol Sakala & Maureen P. Corry, *Overdue: Medicaid and Private Insurance Coverage of Doula Care to Strengthen Maternal and Infant Health*, 25 J. Perinatal Educ. 145, 147-8 (2016).
[345] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of sex, as defined under Title IX of the Education Amendments of 1972, 20 U.S.C. 1681 et seq., which encompasses discrimination on the basis of pregnancy status. *See* U.S. Dept. of Education, *Sex Discrimination: Overview of the Law*, bit.ly/3wmjTGM; 34 CFR §106.30 (defining sexual harassment as conduct on the basis of sex, including sexual assault); 20 U.S.C. §1092(f)(6)(A)(v).

> against that person's will in instances where the victim is incapable of giving consent because of [their] temporary or permanent mental or physical incapacity.[346]

Where a healthcare provider commits sexual assault with an object against a pregnant patient, OCR may use its enforcement authority to hold that healthcare provider and the facility where the assault occurred accountable. There are also times when a provider simply uses the pretext of pregnancy or reproductive health care to commit an assault that has no clinical rationale, as in the case of a provider perpetrating an assault for their own sexual gratification, or in the case of vaginal exams performed for training purposes on an unconscious person.[347] These warrant OCR investigation and accountability as sex-discrimination but are not discussed here in further detail. There are also several ways sexual assault occurs in the context of pregnancy and birth where the clinical context obscures the assault. These are described in more detail below.

(b) Obstetric Conduct that Constitutes Sexual Assault with an Object.

(3) Digital Penetration of the Vagina by a Healthcare Provider without the Patient's Consent

Obstetric care providers use their hands, typically gloved, as instruments of assessment and intervention in determining the health status of pregnant and laboring patients and their fetuses.[348] For example, they use their fingers to penetrate patients' vaginas and feel with their fingertips to assess the extent to which the cervix has opened and thinned in preparation for birth, to determine the position of the fetus, and at times attempt to induce labor with a "membrane sweep" consisting of inserting a finger through a patient's cervix and sweeping their fingers to detach the membrane connecting the amniotic sac to the uterine wall.[349] Because in these instances healthcare providers use their hands as clinical tools, they should be considered "instruments" pursuant to the NIBRS definition of sexual assault with an object. The fact that in some jurisdictions, medical providers have protection from civil and criminal liability for actions like this, that would otherwise constitute sexual assault, underscores both the discriminatory context of perinatal care, and the need for OCR oversight. It can be confounding to legal redress that the provider gets no sexual gratification from this violation, *but that is not required by the definition*. Especially as a form of discrimination in healthcare, the mental state of the provider should not be considered. When providers fail to seek and receive consent for penetration of the vagina, regardless of the medical purpose, and proceed to penetrate the vagina anyway, it is sexual assault.

Cervical checks during labor, continuing vaginal examinations after the patient has withdrawn consent, and forcibly performing cervical checks in disregard of patients' verbal objections or attempts to physically move away from the provider are forms of sex-based

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[346] 20 U.S.C. §1092(f)(6)(A)(v); NIBRS Definitions (2012) U.S. Department of Justice, Federal Bureau of Investigation Uniform Crime Reporting Program, National Incident-Based Reporting System, bit.ly/3PlsySy.
[347] *See e.g.* Jan Ransom, *19 Women Accused a Gynecologist of Abuse. Why Didn't He Go To Prison?*, N.Y. TIMES (Oct. 22, 2019), nyti.ms/3Nf7LOK.; Maya M. Hammoud et al., *Consent for Pelvic Examination Under Anesthesia by Medical Students*, 134 Obstetrics & Gynecology 1303 (Dec. 2019).
[348] Julia Hutchison, Heba Mahdy & Justin Hutchison, *Stages of Labor* (2021).
[349] Julia Hutchison, Heba Mahdy & Justin Hutchison, *Stages of Labor* (2021).; Elaine Finucane, et al., *Membrane Sweeping for Induction of Labor*, 2020 Cochrane Database Syst. Rev. (2020).

discrimination.[350] Examples include performing vaginal exams while a birthing person is experiencing a contraction, ignoring the patient's cries of, "No. Stop!"[351] In these instances, using a finger or fingers to penetrate a patient's vagina without their consent, or over their objections, plainly meets the prong of "against that person's will" within the NIBRS definition of sexual assault with an object.

A patient's reasons for withholding consent are irrelevant to the NIBRS standard, though it is worth noting that patients often have well-considered reasons for wishing to avoid or minimize vaginal exams during labor, including an increased risk of infection or sepsis in the neonate, or a desire to avoid being restricted in their movements.[352] Not to mention, the desire to minimize triggering memories and trauma from previous sexual assaults as discussed below.

Likewise, birthing people in many states report providers sweeping their membranes during cervical checks without any advance discussion or consent process, and as a result experiencing pain, bleeding and loss of the opportunity to decide for themselves whether to attempt to induce labor.[353] Like cervical checks, unconsented membrane sweeps constitute unlawful penetration of the genital opening of the body of a pregnant person against that person's will, and meet the standard of sexual assault with an object under the NIBRS definition.

> (2) Instrumental Penetration of the Vagina by a Healthcare Provider without the Patient's Consent.

At times, providers use other tools to perform interventions on a pregnant person, including amnihooks to break a pregnant person's bag of waters, forceps or vacuum extractor to grasp the baby's head and pull the baby toward the vaginal opening, and surgical scissors to cut episiotomies.[354] Birthing people report having these instruments and others used on them during labor without their consent or over their objections.[355] These instances clearly meet the NIBRS definition of sexual assault with an object, as they involve the use of medical instruments to penetrate the genital openings of birthing people against their will.

One high profile example of a provider penetrating their patient's genitals with an instrument against the patient's will is the case of Kimberly Turbin. Ms. Turbin was in labor and at the pushing stage when her provider said he was going to cut an episiotomy.[356] Ms. Turbin loudly objected, saying, "No, don't cut me!"[357] Her doctor responded, "I am the expert here...why can't I do it?" and then proceeded to cut Ms. Turbin's perineum twelve times.[358] All

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[350] Henci Goer, *Cruelty in Maternity Wards; Fifty Years Later*, 19 J. Perinatal Educ. 33 (2010).; Elizabeth Kukura, *Obstetric Violence*, *supra* note 122.
[351] *See* Goer, *Cruelty in Maternity Wards; Fifty Years Later*, *supra* note 350.
[352] Lauren Jansen, et al., *First: Do No Harm: Interventions During Childbirth*, 22 J. Perinatal Educ. 83 (2013).
[353] Kukura, *Obstetric Violence*, *supra* note 122, at 743-47 (2018).
[354] Heba Mahdy, Christopher Glowacki & Frederick U. Eruo, *Amniotomy* (2022).
[355] Kukura, *Obstetric Violence*, *supra* note 122, at 743-47 (2018); Allison B. Wolf & Sonya Charles, *Childbirth Is Not an Emergency: Informed Consent in Labor and Delivery*, 11 Int'l J. of Feminist Approaches to Bioethics 23 (2018).
[356] Jocelyn Wiener, *'Don't Cut Me!': Discouraged by Experts, Episiotomies Still Common in Some Hospitals*, KAISER HEALTH NEWS (2016), bit.ly/3sBd03j.
[357] *Id*.
[358] Rebecca Grant, *Ethics of the Delivery Room: Who's in Control When You're Giving Birth?*, INDEPENDENT (Dec. 18, 2017), bit.ly/3wxk4Pu.

of this was captured on video, and Ms. Turbin later sued her doctor for assault and battery, and then settled the case out of court.[359]

Another example of unconsented penetration involves the so-called "husband stitch" - an extra stitch added during repair of a perineal tear or episiotomy supposedly intended to tighten the vaginal opening for the benefit of the birthing person's future sexual partners.[360] The prevalence of this practice is unclear, as the husband stitch has not received much study, but the concept of the husband stitch is widely known in the obstetric community, and instances of patients receiving a husband stitch have been documented.[361] Even where a person consents to a perineal repair, the placing of additional stitches for a purpose other than repair, which are not intended for clinical benefit and involve additional risks exceeds the patient's consent and therefore constitutes unlawful instrumental penetration of their genitals against their will under the NIBRS definition.

As with refusals of digital penetration, the reasons a patient might choose to refuse instrumental penetration are irrelevant to whether the unconsented instrumental penetration constitutes sexual assault. Nevertheless, there are compelling reasons for patients to refuse such interventions. Amniotomies increase the risk of infection and limit the amount of time a person can safely remain in labor, and their effectiveness of inducing or augmenting labor is questionable under most circumstances.[362] Forceps and vacuum-assisted deliveries can cause significant injuries to both the birthing person and their baby.[363] Episiotomies have been found to have little to no benefit to birthing people, while increasing the risk of tears requiring repair.[364] These procedures are risky, and to impose their associated risks on a birthing person without that person's consent, and worse – to do so in the process of penetrating their genitals against their will – is an extreme violation that OCR should use its enforcement authority to prevent.

(3) Holding a Baby into a Birthing Person's Vagina as Forcible Genital Penetration.

Another example of sexual assault during birth involves healthcare providers holding babies into birthing people's vaginas against their will, usually to ensure that a physician would be present for the birth. There are several published accounts of birthing people being told not to push, but instead to hold their babies in, forcing birthing people to cross their legs to prevent

[359] Kaitlin Stanford, *Women Forced into Episiotomy Slaps OB with Lawsuit*, BUSTLE (June 9, 2015), bit.ly/38uWPh8; Beth Greenfield, *Woman Forced Into Violent Episiotomy Settles with Doctor*, YAHOO NEWS (Mar. 15, 2017), yhoo.it/3LeAm5d.
[360] Carrie Murphy, *The Husband Stitch Isn't Just a Horrifying Childbirth Myth*, HEALTHLINE (2018), bit.ly/3MjRuI2.
[361] *Id.*; Mary Halton, *The 'Husband Stitch' Leaves Women in Pain and Without Answers*, VICE NEWS (Apr. 26, 2018), bit.ly/3FUu3mj; Alex Archambault, *A Woman Says her Vagina Was Sewn Tighter After Childbirth Without Her Knowledge – and It's More Common Than You Think*, INSIDER (July 25, 2018), bit.ly/38zoVYq.
[362] *See* Heba Mahdy, Christopher Glowacki & Frederick U. Eruo, *Amniotomy*, *supra* note 354.
[363] Unzila A. Ali & Errol R. Norwitz, *Vacuum-Assisted Vaginal Delivery*, 2 Review Obstetrics & Gynecology 5 (2009).
[364] Katherine Hartmann, et al., *Outcomes of Routine Episiotomy: A Systematic Review*, 293 J. Am. Med. Ass'n 214 (2005).

birth, and even using their hands to hold a baby in the birth canal despite the fact that this is counter to the physiologic imperative, it also causes pain and lacks medical necessity.[365]

One extreme example of this was the case of Caroline Malatesta, who was on the cusp of delivering her baby when a nurse began pushing her baby's head back into Ms. Malatesta's vagina, and then held the baby inside her vagina for six minutes, all while Ms. Malatesta screamed at the nurse to stop.[366] Ms. Malatesta was severely and permanently injured, and was ultimately awarded a $16 million civil judgment against the hospital where the assault took place.[367] Such conduct meets the NIBRS definition of sexual assault with an object: When a provider holds a baby into a patient's vagina over a birthing person's objections, the baby itself is an object being used to forcibly penetrate the birthing person's genital opening against that person's will. As another instance of sexual assault with an object during birth, this conduct by providers and healthcare facilities should be met with OCR enforcement.

Not only do the acts discussed above meet the NIBRS definition of sexual assault, they also meet the definition of sexual violation set by the American College of Obstetricians and Gynecologists (ACOG), which sets professional practice guidelines for obstetricians in the United States.[368] That opinion includes in its definition of sexual violation the touching of "any sexualized body part for any purpose other than examination or treatment, or when the patient has refused or withdrawn consent."[369] Furthermore, when providers use instruments, including their hands, to force obstetric procedures on their patients, patients *experience* this forcible genital touching and penetration as sexual assault.[370] To that end, patients who have experienced unconsented examinations and interventions during childbirth experience many of the same outcomes as other sexual assault victims, including traumatophobia, dissociation, anxiety, depression, post-traumatic stress disorder, flashbacks, distress on the anniversary of birth trauma, relationship problems, self-blame, not reporting their assault, and becoming an advocate to prevent others from having similar traumatic experiences.[371] Not only does the provider conduct described in the above sections meet the technical definition of sexual assault under OCR's purview, it produces harms of the nature that OCR enforcement is intended to prevent. The persistence of- and lack of accountability for- these forms of mistreatment expose the fact that these are forms of discrimination based on sex.

(c) Examples of Conduct During Obstetric Care that Compound Sexual Assault.

As discussed above, OCR has enforcement authority over sex discrimination in healthcare, which includes discrimination based on pregnancy status as well as sexual

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[365] Kimberly Lawson, *Women in Labor Can't Hold in Their Babies. Nurses Tell Them to Do it Anyway*, VICE NEWS (July 16, 2019), bit.ly/3LhdVfF; Theresa Morris et al., *Screaming, 'No! No!' It was Literally Like Being Raped: Connecting Sexual Assault Trauma to Coerced Obstetric Procedures*, 00 Soc. Problems 1 (2021).; Anna Claire Vollers, *Caroline Malatesta Opens Up About Birth Trauma, Bait-and-Switch Advertising of Alabama Hospital*, AL.COM (Aug. 9, 2016), bit.ly/3NhkdNI.

[366] Sarah Yahr Tucker, *There Is a Hidden Epidemic of Doctors Abusing Women in Labor, Doulas Say*, VICE NEWS (2018), bit.ly/3NhQvrW.

[367] *Id*.

[368] American College of Obstetricians & Gynecologists, *Sexual Misconduct: ACOG Committee Opinion Number 796*, 135 Obstetrics & Gynecology e43 (2020) [hereinafter "ACOG, *Sexual Misconduct*"].

[369] *Id*.

[370] *See* Morris, et al., *supra* note 365.

[371] *See* Morris, et al., *supra* note 365.

harassment.[372] Sexual harassment falling under OCR's enforcement authority includes "[u]nwelcome conduct determined by a reasonable person to be so severe, pervasive and objectively offensive that it effectively denies a person equal access" to any health program or activity that receives federal financial assistance.[373] Beyond overt physical violations that themselves constitute sexual assault, healthcare providers may engage in conduct that meets this definition of sexual harassment.

One example of such harassment involves physicians making degrading sexual comments to their patients, such as, "Come on, you need to open your legs, obviously you didn't mind that nine months ago."[374] ACOG has specifically addressed this behavior in its opinion on sexual misconduct, categorizing as sexual impropriety, "making sexual comments about a patient's body…, making sexualized or sexually demeaning comments to a patient…during an examination."[375] A reasonable person could find demeaning sexual comments by a provider during labor, particularly if they go unchallenged by other staff present, sufficiently severe, pervasive and objectively offensive that they are unable to access on an equal basis the healthcare they need during the remainder of that time under the care of that provider or facility.

Similarly, birthing people's trauma from past sexual assault may be triggered by unconsented or insensitively performed vaginal examinations, forcing certain body positions, and restricting patients' movement during labor.[376] Loss of control is a common significant trigger of sexual abuse trauma, so failing to safeguard a patients' control over who touches their body, when they are touched, and the types of touch they experience can inflict additional trauma.[377] Taken together, this conduct may rise to the level of so severe, pervasive and objectively offensive as to deny the patient equal access to healthcare services, and therefore be subject to OCR enforcement against both provider and facility.

5. Sex-Selective and Nonconsensual Drug Testing and Reporting.

(a) The Sex-Selective Application of Drug Tests Against Pregnant and Postpartum Patients Violates Section 1557's Prohibition on Sex Discrimination.

Finally, sex-selective and non-consensual drug testing and reporting against pregnant and postpartum patients constitutes sex-discrimination warranting OCR attention. Hospitals routinely single out pregnant and postpartum patients for drug testing and report the results of those tests to state agencies, including civil child welfare and criminal law enforcement agencies.[378] There are

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[372] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of sex, as defined under Title IX of the Education Amendments of 1972, 20 U.S.C. 1681 et seq., which encompasses discrimination on the basis of pregnancy status. *See* U.S. Dept. of Education, *Sex Discrimination: Overview of the Law*, bit.ly/3wmjTGM; 34 CFR §106.30 defining sexual harassment as conduct on the basis of sex, including sexual assault; 20 U.S.C. §1092(f)(6)(A)(v).

[373] 34 CFR §106.30(a)(2).

[374] *See* Goer, *Cruelty in Maternity Wards; Fifty Years Later*, *supra* note 350.

[375] *See* ACOG, *Sexual Misconduct*, *supra* note 368.

[376] Elsa Montgomery, Catherine Pope, & Jane Rogers, *The Re-Enactment of Childhood Sexual Abuse in Maternity Care: a Qualitative Study*, 15 BMC Pregnancy and Chilbirth 194 (2015); *See* Goer, *Cruelty in Maternity Wards; Fifty Years Later*, *supra* note 350; Kukura, *Obstetric Violence*, *supra* note 122 at 743-47.

[377] *See* Montgomery, Pope & Rogers, *The Re-Enactment of Childhood Sexual Abuse in Maternity Care*, *supra* note 376.

[378] Paltrow & Flavin, *Arrests of and Forced Interventions on Pregnant Women in the United States, 1973–2005*, *supra* note 42, at 326-27 ("Far from being a bulwark against outside intrusion and protecting patient privacy and

no studies or reports documenting routine drug testing and reporting of any other subset of patients, including fathers, who seek emergency or other health care at those hospitals. The sex-selective drug testing and reporting of perinatal patients is a form of discrimination on the basis of sex that plainly violates Section 1557.

HHS applies Section 1557's prohibition on sex discrimination in healthcare in the same manner that it applies Title IX's prohibition on sex discrimination in education. HHS's Title IX implementing regulations provide, in relevant part, "A recipient shall treat pregnancy, childbirth, false pregnancy, termination of pregnancy and recovery therefrom in the same manner and under the same policies as any other temporary disability with respect to any medical or hospital benefit, service, plan or policy which such recipient administers, operates, offers, or participates in."[379] So, for instance, if a hospital does not drug test a patient who arrives at the emergency room with a broken leg but drug tests a patient who arrives to the hospital in labor, the hospital engages in sex discrimination by failing to treat pregnancy "in the same manner and under the same policies as any other temporary disability."[380]

There is no justification for subjecting pregnant and postpartum patients to drug tests, when those tests are not routinely administered to any other patients and do not come with any clinical benefit to the pregnant patient or fetus. Hospitals do not routinely drug test patients outside of the labor and delivery department, even though many such patients are parents.[381] Nor do hospitals routinely drug test fathers or other non-birthing caregivers who are present during labor and delivery. The fact that hospitals do not drug test emergency room patients, fathers, or other caregivers who are present at labor and delivery undermines any putative claim that such tests are necessary to protect hospital patients' children from "neglectful" caregivers. Hospitals that subject only pregnant and postpartum patients to drug tests make the indefensible assumption that a drug test functions as a parenting test for those patients and only those patients. In reality, drug tests only provide information about past use of a substance, they do not provide information about parenting ability for *any* patients.[382]

The sex-selective application of drug tests against pregnant and postpartum patients also violates Section 1557 because it rests on illicit and outmoded gender stereotypes. Specifically, medical providers that single out pregnant and postpartum patients for drug testing assume that only a mother's substance use is relevant to an infant's safety and wellbeing because childrearing is a woman's domain. As both Congress and the Supreme Court have recognized, state actors engage in unlawful sex discrimination when they enact policies that are attributable "to the

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confidentiality, we find that health care and other 'helping' professionals are sometimes the people gathering information from pregnant women and new mothers and disclosing it to police, prosecutors, and court officials."); Movement for Family Power, et al., *Family Separation in the Medical Setting: The Need for Informed Consent* (Nov. 24. 2019), https://bit.ly/39NYnjd ("[S]tudies confirm that that doctors frequently misunderstand their responsibility under [the Child Abuse Prevention and Treatment Act], and States have widely expanded the scope of this law further consecrating a practice of drug testing and reporting in hospital settings that is not legally required, and further that risks the wellbeing of parents and their newborns.") (*citing* Lloyd, et al., *The Policy to Practice Gap: Factors Associated with Practitioner Knowledge of CAPTA 2010 Mandates for Identifying and Intervening in Cases of Prenatal Alcohol and Drug Exposure*, 99 J. Contemp. Soc. Servs. 232 (July 2018)).

[379] 45 CFR § 86.40(b)(4).

[380] *Id*.

[381] Elizabeth Brico, *Doctors Drug Test Black and Poor Families at Higher Rates, Risking Family Separation*, TALK POVERTY (Dec. 1, 2021), https://bit.ly/3kIhTmL.

[382] *See generally* Sangoi, *Ground Zero Report*, *supra* note 42.

pervasive sex-role stereotype that caring for family members is women's work."[383] The fact that hospitals do not routinely subject men to drug tests—irrespective of their status as fathers—reflects "parallel stereotypes presuming a lack of domestic responsibilities for men."[384] As Title IX's prohibition on sex discrimination encompasses a prohibition on treating male and female students differently on the basis of sex stereotypes,[385] Section 1557 likewise prohibits hospitals from treating male and female patients differently on the basis of sex stereotypes.

(b) Hospitals That Disproportionately Drug Test and Report Pregnant and Postpartum Birthing People of Color Also Violate Section 1557's Prohibition on Race Discrimination.

Even hospitals that have facially neutral drug testing policies disproportionately target pregnant and postpartum patients of certain races for drug testing and reporting. This practice also violates Section 1557's prohibition on race discrimination.[386] Studies show that hospitals disproportionately subject birthing people who do not fit the white, middle-class stereotype of the "good" American mother to drug testing and reporting.[387] Indeed, in one study in which urine toxicology tests were collected over a 6-month period, it was found that despite similar rates of substance use among Black patients and white patients in the study, Black birthing people were reported to social services at approximately 10 times the rate for white birthing people.[388] Hospitals that disproportionately test and report pregnant and postpartum people of color thus also engage in illicit race discrimination in violation of Section 1557.

(c)The Drug Testing of Perinatal Patients Is Not Legally Required, Often Occurs Without Informed Consent, and Leads to Punitive Consequences.

The practice of drug testing labor and delivery patients and reporting test results to state authorities is pervasive, despite the fact that testing is rarely clinically indicated and reporting is often not legally required.[389] Moreover, hospitals often perform these tests without following any

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[383] Nev. Dept. of Human Res. v. Hibbs, 538 U.S. 721, 731-35 (U.S. 2003) (upholding provisions of the Family Medical Leave Act as a valid exercise of Congress's authority to enact legislation to further the guarantees of the Equal Protection Clause in light of "States' record of unconstitutional participation in, and fostering of, gender-based discrimination in the administration of leave benefits").

[384] *Id*. at 736.

[385] *See, e.g.*, Grimm v. Gloucester Cty. Sch. Bd., 972 F.3d 586, 616-17 (4th Cir. 2020); Whitaker v. Kenosha Unified Sch. Dist. No. 1 Bd. of Educ., 858 F.3d 1034 (7th Cir. 2017); Dodds v. U.S. Dep't of Educ., 845 F.3d 217 (6th Cir. 2016).

[386] *See* Phillip J. Hilts, *Hospital Put on Probation Over Tests on Poor Women*, N.Y. TIMES (Oct. 5, 1994), https://nyti.ms/3OKlY6L. (describing how the Department of Health and Human Services Office for Civil Rights determined that the Medical University of South Carolina violated the civil rights of Black and poor pregnant patients by drug testing them without their knowledge or consent and threatening them with public exposure and jail if they did not complete drug treatment and submit to continuous drug testing).

[387] Kathi Harp & Amanda M Bunting, *The Racialized Nature of Child Welfare Policies and the Social Control of Black Bodies*, 27 Soc. Pol. 258 (June 2020).

[388] Ira J. Chasnoff et al., *The Prevalence of Illicit-Drug or Alcohol Use during Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida*, 322 NEW ENGLAND J. OF MED. 1202 (Oct. 1990).

[389] *See, e.g.*, New York State Department of Health, *NYS CAPTA CARA Information & Resources*, https://on.ny.gov/3ymjBSO (explaining that the American College of Obstetricians & Gynecologists does "not recommend routine toxicology testing during pregnancy and delivery, or for the newborn"; that a hospital need not collect data on newborns who have positive toxicology screens in the absence of symptoms of substance withdrawal

consistent guidelines; without seeking pregnant and postpartum patients' specific, informed consent; and without providing notice of the potential legal repercussions that could flow from a positive drug test result.[390]

As a matter of medical ethics, law, respect for patient privacy, and the best interests of children and families, medical providers should never seek information about a perinatal patient's substance use in the absence of medical necessity.[391] The fact of pregnancy itself does not provide a medical justification for testing. The limited circumstances in which it may be medically necessary for providers to obtain information about substance use include when such information is essential to a differential diagnosis and/or when it would change the course of medical treatment.[392] Even in such circumstances, providers should give patients the opportunity to voluntarily disclose substance use through a confidential conversation in lieu of submitting to drug testing. Drug testing without a patient's knowledge and informed consent is appropriate only in the rare scenario in which the patient is obtunded or otherwise incapable of providing informed consent.[393] That such testing occurs routinely during pregnancy, and only of the pregnant patient and not the other person who contributed genetic material to the pregnancy, in the absence of medical necessity and informed consent is evidence that this practice violates civil rights laws.

It is also clearly established both in law and ethics that hospitals should not report drug test results to civil child welfare authorities in the absence of a legal requirement to do so and should never report such results to criminal law enforcement.[394] And yet, this happens regularly.

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or a diagnosis of Neonatal Abstinence syndrome or Fetal Alcohol Spectrum Disorder, and even then that the hospital need only collect aggregate de-identified data; and that "substance use alone . . . is not evidence of child maltreatment" and need not be reported to state agencies); New York City Dep't of Health, *Reporting and Planning Requirements for Newborns Prenatally Exposed to Substances and Their Caregivers*, https://on.nyc.gov/3vNbflq ("If a medical provider or other mandated report learns . . . that the newborn may have been exposed to substances in utero, but the newborn does not show physiological signs of that exposure, the [Child Abuse Prevention and Treatment Act] does not apply . . . . A positive toxicology result for a parent or a newborn, by itself, does not constitute reasonable suspicion of child abuse or maltreatment, and thus does not necessitate a report to the SCR . . . . Similarly, a maternal history of past drug use or disclosure of current drug use is not sufficient, by itself, to warrant a report to the SCR.").

[390] *See generally* Movement for Family Power, et al., *Family Separation in the Medical Setting, supra* note 378.

[391] *Id.*; *see also* New York State Department of Health, *NYS CAPTA CARA Information & Resources,* https://on.ny.gov/3ymjBSO ("Toxicology testing should only be performed when medically indicated."); *Elaine W. v. Joint Diseases N. Gen. Hosp., Inc.*, 613 N.E.2d 523, 525 (N.Y. 1993) (holding that a hospital policy that "discriminates against pregnant women by treating them differently from others solely because they are pregnant . . . constitutes facial sexual discrimination" and that the policy's differential treatment must be "based upon medical necessity, not upon generalizations associated with pregnant women");

[392] *See* Mishka Terplan et al., *Prenatal Substance Use: Exploring Assumptions About Maternal Unfitness*, 9 Substance Abuse 1 (2015) ("Proper identification of pregnant women with a SUD is necessary in order to facilitate treatment . . . However, equating SUD with maternal unfitness is inconsistent with how other chronic illnesses are conceptualized and managed during pregnancy, reflecting the continued perception of prenatal substance use and SUD as moral failures rather than medical conditions.").

[393] American College of Obstetricians and Gynecologists, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period* (2020) [hereinafter: "ACOG, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*"] ("Before performing any test on the pregnant individual or neonate, including screening for the presence of illicit substances, informed consent should be obtained from the pregnant person or parent.").

[394] *See* ACOG, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period.* ("Policies and practices that criminalize individuals during pregnancy and the postpartum period create fear of punishment that compromises [the patient-practitioner] relationship and prevents many pregnant people from seeking vital health services."); American Medical Association, *Policy Statement H 420.970, Treatment Versus*

Safeguards on drug testing and reporting are essential in light of the punitive outcomes that pregnant and postpartum patients face as a result of the "test and report" system.[395] National Advocates for Pregnant Women (NAPW) has documented more than 1,600 instances since 1973 in which women were arrested, prosecuted, convicted, detained, or forced to undergo medical interventions that would not have occurred but for their status as pregnant persons whose rights state actors assumed could be denied in the interest of fetal protection.[396] Those assumptions are wrong and violate pregnant people's constitutional and civil rights. A significant number of the arrests and prosecutions identified involved allegations of the use of controlled substances, even though the vast majority of state criminal laws do not make using drugs—as opposed to possessing drugs—illegal.

Accordingly, these prosecutions sought to transform drug use or dependency by one group of people—pregnant people—into criminal "child abuse," "chemical endangerment" or "drug distribution."[397] Moreover, the substances in question were not controlled *because* of concerns about fetal development. Indeed, scientific evidence has compellingly refuted beliefs that such substances cause fetal harm or pregnancy loss and establishes that associated risks are no greater or less than those for other substances commonly used.[398] Testing, reporting and prosecuting in these cases is discriminatory across multiple domains which may include sex, race, national origin, age, and disability, so heightened attention to this issue is warranted.

While, as discussed above, targeting pregnant patients for drug testing is discriminatory in itself, we note that the *manner* of testing also has discriminatory elements and has deprived pregnant patients of guarantees of consistency and accuracy in that testing. Indeed, hospitals that selectively test a subset of their patients—pregnant ones—generally also have policies regarding workplace drug testing for job applicants and employees. In 1993, the U.S. Department of Health and Human Services Substance Abuse Mental Health Services Administration (SAMHSA) convened an expert consensus panel to improve drug treatment for pregnant people. The panel specifically addressed the question of whether pregnant and postpartum people should routinely

Criminalization – Physician Role in Drug Addiction During Pregnancy (last modified 2020) ("It is the policy of the AMA to reconfirm its position that drug addiction is a disease amenable to treatment rather than a criminal activity; . . . [and] to oppose legislation which criminalizes maternal drug addiction or requires physicians to function as agents of law enforcement - gathering evidence for prosecution rather than provider of treatment."); American Medical Association, *Policy Statement H-420.950, Substance Use Disorders During Pregnancy* (last modified 2019) ("Our AMA will oppose any efforts to imply that the diagnosis of substance use disorder during pregnancy represents child abuse; support legislative and other appropriate efforts for the expansion and improved access to evidence-based treatment for substance use disorders during pregnancy; oppose the removal of infants from their mothers solely based on a single positive prenatal drug screen without appropriate evaluation; and advocate for appropriate medical evaluation prior to the removal of a child, which takes into account the desire to preserve the individual's family structure, the patient's treatment status, and current impairment status when substance use is suspected.").

[395] *See* Movement for Family Power, et al., *Family Separation in the Medical Setting, supra* note 378.

[396] National Advocates for Pregnant Women, *Arrests and Deprivations of Liberty of Pregnant Women, 1973-2020* (Sept. 2021), bit.ly/arrests1973to2020.

[397] Paltrow & Flavin, *Arrests of and Forced Interventions on Pregnant Women in the United States, 1973–2005, supra* note 42, at 323.

[398] *See* Mishka Terplan & Tricia Wright, *The Effects of Cocaine and Amphetamine Use During Pregnancy on the Newborn: Myth versus Reality*, 30 J. Addictive Diseases 1 (Jan. 2011); *see also* National Advocates for Pregnant Women,, *Drug Use and Pregnancy* (2021).

be tested for evidence of drug use.[399] While the panel recognized that certain criteria were used by some health care institutions to test some women, the panel did not recommend adopting any of these criteria as a basis for testing pregnant women nor did it endorse the routine drug testing of pregnant women.[400]

The SAMHSA expert panel advised health care institutions that do conduct routine alcohol and drug testing to do so in accordance with the standards used for urine drug testing in the workplace as proscribed by the federal workplace drug testing guidelines.[401] Notably, the federal workplace drug testing guidelines establish certain cut-off levels to establish a true positive result, require a confirmatory test, and require that the person tested have the opportunity to challenge results and have a re-test.[402] In contrast, pregnant patients and postpartum parents have not even been afforded these safeguards.[403]

(d) Singling Out Pregnant and Postpartum Patients for Drug Testing and Reporting Undermines—Rather Than Advances—Maternal and Infant Health.

Hospitals cannot justify singling out pregnant and postpartum patients for drug testing and reporting on the grounds that such actions further maternal or infant health. In fact, all major medical and public health groups oppose punitive responses to pregnancy and drug use and agree that such approaches undermine the health of pregnant people, children, and families. For instance, the American Medical Association,[404] American Nurses Association,[405] American Psychological

[399] Ctr. for Substance Abuse Treatment, Substance Abuse & Mental Health Serv. Admin., Dep't Health & Human Servs., *Pregnant, Substance-Using Women*, Treatment Improvement Protocol (TIP) Series 2, Guideline 15, DHHS Publication No. (SMA) 95-3056 (1993, *reprinted in* 1995).
[400] *Id.* at 48.
[401] *Id.*; *see Mandatory Guidelines for Federal Workplace Drug Testing Programs*, 69 FR 19643 (Apr. 13, 2004).
[402] *Id.*
[403] As a result, investigative reports have identified a high incidence of false (simply wrong) or innocent (positive for a prescribed drug/ over the counter medication) positives among pregnant women and newborns *See e.g.*, Troy Anderson, *False Positives Are Common in Drug Tests on New Moms*, LA DAILY NEWS (June 28, 2008), https://bit.ly/3xUqvwN.
[404] American Medical Association, *Policy Statement H-420.962, Perinatal Addiction - Issues in Care and Prevention* (2019) ("Transplacental drug transfer should not be subject to criminal sanctions or civil liability…."); American Medical Association, *Policy Statement H-420.969, Legal Interventions During Pregnancy* (last modified 2018) ("Criminal sanctions or civil liability for harmful behavior by the pregnant woman toward her fetus are inappropriate. Pregnant substance abusers should be provided with rehabilitative treatment appropriate to their specific physiological and psychological needs.").
[405] American Nurses Association, *Position Statement: Non-punitive Treatment for Pregnant and Breast-feeding Women with Substance Use Disorders* (2017) ("Contrary to claims that prosecution and incarceration will deter pregnant women from substance use, the greater result is that fear of detection and punishment poses a significant barrier to treatment.").

Association,[406] American Psychiatric Association,[407] and American Academy of Pediatrics[408] have all concluded that punitive and criminal law responses—as opposed to responses grounded in public health—pose barriers to treatment, are in effective at deterring substance use, and put mothers and children at greater risk of harm.[409]

As the American College of Obstetricians and Gynecologists ("ACOG") explains, "a positive drug test should not be construed as child abuse or neglect" and punitive responses pose "serious threats to people's health and the health system itself … [by] erod[ing] trust in the medical system, making people less likely to seek help when they need it."[410] For this reason, the ACOG Committee on Health Care for Underserved Women has concluded:

> Seeking obstetric–gynecologic care should not expose a woman to criminal or civil penalties, such as incarceration, involuntary commitment, loss of custody of her children, or loss of housing . . . . The use of the legal system to address perinatal alcohol and substance abuse is inappropriate. Obstetrician–gynecologists should be aware of the reporting requirements related to alcohol and drug abuse within their states. In states that mandate reporting, policy makers, legislators, and physicians should work together to retract punitive legislation and identify and implement evidence-based strategies outside the legal system to address the needs of women with addictions.[411]

Facilitating punitive actions against pregnant people and new parents causes real and devastating health consequences by deterring them from seeking healthcare.[412] In particular, the

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[406] American Psychological Association, *Pregnant and Postpartum Adolescent Girls and Women with Substance-Related Disorders* (2020) ("Punitive approaches result in women being significantly less likely to seek substance use treatment and prenatal care due to fear of prosecution and fear of the removal of children from their custody. This places both the mother and her children at greater risk of harm.") (internal citation omitted).
[407] American Psychiatric Association, *Position Statement: Assuring the Appropriate Care of Pregnant and Newly-Delivered Women with Substance Use Disorders* (2019) ("A public health response, rather than a punitive legal approach to substance use during pregnancy is critical.").
[408] American Academy of Pediatrics, Committee on Substance Use and Prevention, *Policy Statement: A Public Health Response to Opioid Use in Pregnancy* (2017) ("The existing literature supports the position that punitive approaches to substance use in pregnancy are ineffective and may have detrimental effects on both maternal and child health.").
[409] National Advocates for Pregnant Women, *Medical and Public Health Group Statements Opposing Prosecution and Punishment of Pregnant Women* (2021).
[410] ACOG, *Opposition to Criminalization of Individuals During Pregnancy and Postpartum Period*, *supra* note 393.
[411] American College of Obstetricians & Gynecologists, Committee on Health Care for Underserved Women, *Comm. Opinion No. 473: Substance Abuse Reporting and Pregnancy: The Role of the Obstetrician-Gynecologist* (2014).
[412] *See e.g.*, *id.*; Am. Med. Ass'n, *supra* note 404; Am. Nurses Ass'n., *supra* note 405; Am. Psych. Ass'n, *supra* note 406; Am. Psychiatric Ass'n, *supra* note 407; Am. Acad. of Pediatrics, *supra* note 408; Rebecca L. Haffajee et al., *Pregnant Women with Substance Use Disorders—The Harm Associated with Punitive Approaches*, 384 N. Engl. J. Med. 2364 (2021); Meghan Boone & Benjamin J. McMichael, *State-Created Fetal Harm*, 109 Geo. L. J. 475 (2021); Laura J. Faherty et. al., *Association of Punitive and Reporting State Policies Related to Substance Use in*

fear that medical authorities will report them to child welfare providers or criminal law enforcement, as discussed above, leads to coercion and force, and also deters pregnant people from seeking prenatal care or drug treatment services.[413] This fear of penalties also deters parents from bringing their children in for medical care, further undermining family health.[414] It creates a disincentive for pregnant people with actual drug dependency problems from having an open and honest relationship with their prenatal healthcare providers out of fear that disclosure will lead to criminal prosecutions or loss of custody of their children, because often that fear is well founded.[415]

Punitive laws that drive a wedge between patients and their doctors have demonstrable negative impacts on fetal and neonatal health. For example, empirical research found that Tennessee's "fetal assault" law "resulted in twenty fetal deaths and sixty infant deaths" in 2015 alone.[416] Another empirical study found a higher prevalence of neonatal abstinence syndrome (NAS) in states with punitive policies in effect.[417]

In sum, there is universal medical consensus opposing punitive responses to pregnancy and drug use because they are inhumane, discriminatory, and cause real harm to maternal, fetal, and child health, and because they replicate and further entrench discriminatory systems that target people with childbearing capacity, and specifically, women and TGD people of color. This country's medical and public health authorities agree that the provision of care for pregnant and postpartum people, including those who have experienced pregnancy loss, should never result in an arrest. Accordingly, hospitals cannot justify testing and reporting pregnant and postpartum

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Pregnancy With Rates of Neonatal Abstinence Syndrome, JAMA OPEN NETWORK (2019), https://bit.ly/3vMCRqN; Martha A. Jessup, *Extrinsic Barriers to Substance Abuse Treatment Among Pregnant Drug Dependent Women*, 33 J. Drug Issues 285 (2003) (finding that women identified fear of punitive actions from helping institutions and individuals as a major barrier to prenatal care); Sarah Roberts, *"You Have to Stop Using Before You Go to the Doctor": Barriers to Prenatal Care for Women Who Use Drugs During Pregnancy*, Presentation at Am. Public Health Ass'n Annual Meeting (Nov. 6, 2007) ("For women who want a healthy baby and want to reduce or stop their drug use, fear of being reported to CPS is an additional barrier to care.").

[413] *See id*.

[414] *See id.*

[415] *Id.*; *see also* Sarah E. Wakeman et al., *When Reimagining Systems of Safety, Take a Closer Look at the Child Welfare System*, HEALTH AFFAIRS (Oct. 7, 2020), https://bit.ly/3LPD7Lz; Sheigla Murphy & Marcia Rosenbaum, *Pregnant Women on Drugs: Combating Stereotypes and Stigma*, at 89 (1998) (concluding based on interviews with 120 women who were pregnant and used drugs that "[t]he women most in need of services – those most heavily involved in the drug life – were most alienated from prenatal care. Few felt they could disclose their drug use without risking custody loss or stigma.").

[416] Boone & McMichael, *State-Created Fetal Harm*, *supra* note 412, at 501, 514; *see also* Wendy A. Bach, *Prosecuting Poverty, Criminalizing Care*, 60 William & Mary L. Rev. 3 (Feb. 2019); Orisha Bowers et al., *Tennessee's Fetal Assault Law: Understanding its Impact on Marginalized Women*, SISTER REACH (Dec. 14, 2020) https://bit.ly/3waz1H4.

[417] Faherty et al., *Association of Punitive and Reporting State Policies Related to Substance Use in Pregnancy With Rates of Neonatal Abstinence Syndrome*, *supra* note 412; *see also* Haffajee et al., *supra* note 412; Sarah C.M. Roberts & Cheri Pies, *Complex Calculations: How Drug Use During Pregnancy Becomes a Barrier to Prenatal Care*, 15 Maternal Fetal Health J. 33 (2011).

patients on public health grounds given that such testing and reporting undermines, rather than advances, maternal and infant health.

IV. Discrimination on the Basis of Age Is Widespread Throughout the Perinatal Period and OCR Has the Legal Authority to Address It.

In addition to race-based and sex-based discrimination, obstetric racism and obstetric violence can also manifest as age-based discrimination that is ripe for OCR intervention under the authority granted by Section 1557. Mistreatment and violence in perinatal care services is routinely wrought along the age axis, creating significant health inequities for both childbearing adolescents and older adults. Because the provision of perinatal care to younger and older parents differs "on the basis of age,"[418] the anti-discrimination protections of Section 1557[419] are triggered.[420]

A. Discrimination on the Basis of Age is Widespread in the Context of Pregnancy and Childbirth.

Age-based discrimination occurs as "part of a continuum of the violations that occur in the wider context of structural inequality, discrimination and patriarchy, and are also the result of a lack of proper education and training as well as lack of respect for women's equal status and human rights."[421] The role of gender is clear in international articulations of obstetric violence as discussed above.[422] In the United States, alarming race-based disparities in perinatal outcomes are increasingly being challenged as a manifestation of structural racism.[423] But beyond these more obvious gender and race iterations, obstetric racism and violence is also regularly perpetuated along the age axis, with mistreatment and violence clustered among adolescents and older adults.

Adolescents between the ages of fifteen and nineteen experience some of the highest preterm delivery (10.35% 15-19, 14.39% under 15) and low birth weight (9.98% 15-19, 12.32%

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[418] 42 USC § 6102

[419] 42 USC § 18116(a)

[420] As indicated herein, OCR's authority is clear whether the straightforward Section 1557 "shall not, on the ground [of age] … be subjected to discrimination" mandate applies or the more nuanced anti-discrimination scheme of the Age Discrimination Act. *See* discussion in *Doe v. CVS Pharmacy, Inc.*, 982 F.3d 1204, 1209-1211 (9th Cir. 2020) (finding that the anti-discrimination protections afforded by the ACA "incorporated the legal standards that define discrimination under each" of the statutes referred to in Section 1557 and holding that "Section 1557 does not create a new healthcare-specific anti-discrimination standard").

[421] *See* Šimonović, *A Human Rights-Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence*, *supra* note 3.

[422] *Id.*, at 6-7.

[423] See Black Mamas Matter Alliance, *Setting the Standard for Holistic Care of and for Black Women*, at 4 (April 2018) https://bit.ly/BMMA-18 (asserting that "Racism, racial discrimination, systemic inequities, and social determinants of health contribute to poor maternal health outcomes in the Black community."); *See also* Rhea W. Boyd, et al. *On Racism: A New Standard For Publishing On Racial Health Inequities*, HEALTH AFFAIRS BLOG (July 2, 2020) https://bit.ly/HealthAffairs-20 (starkly noting that "racism kills"); Joia Crear-Perry, et al., *Social and Structural Determinants of Health Inequities in Maternal Health*, 30 J. Women's Health 230, 231 (2021) (describing how structural racism has "endured and adapted over time and continue to shape contemporary access to health-promoting resources and opportunities necessary for optimal Black maternal and infant health outcomes").

under 15) [424] rates compared to all other age groups and the national average.[425] Adults over age 35 experience similarly high preterm delivery (11.58% 35-39, 13.98% 40-44, 21.72% 45-54) and low birth weight (8.84% 35-39, 10.66% 40-44, 17.58% 45-54)[426] rates. The disproportionality of these rates acts as a measure of discrimination on the basis of age.

Scholars of the social sciences have documented how prevailing socio-cultural discourses of motherhood adversely influence the provision of perinatal care to teens[427] and older parents,[428] disparately fueling iatrogenic outcomes (a state of ill health or an adverse effect caused by medical treatment).[429] Indeed, whether young or old, pregnant and birthing individuals at both ends of the age spectrum are constructed as an "at risk" population due to the underlying characteristic of age. Regulation of adolescent childbearing is normalized by framing pregnant teen bodies as "risky bodies" and institutionalized through biomedical care practices that silence young mothers and ignite abusive care.[430] Individuals of "Advanced Maternal Age" (AMA)[431] are similarly pathologized and deemed to be in need of expert surveillance due to a prevailing obstetric discourse that frames pregnancy at or beyond the age of 35 as inherently risky despite there being "no universal consensus" on what defines an AMA pregnancy.[432] The social construction of stigma against younger and older bodies is thus manifest as discrimination on the basis of age and a driving force of obstetric racism and violence.

B. OCR Can and Should Use Its Authority to Address Age-Based Discrimination In the Context of Perinatal Health.

When age limits the available care options, unlawful age-based discrimination occurs. The same occurs when age influences the way that care is delivered. While the specific iteration of discrimination varies based on whether a childbearing individual is a younger parent or an older parent, individuals at both ends of the age spectrum are subjected to age-based discrimination.

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[424] Joyce A. Martin, et al., *Births: Final Data for 2019*, 70 Nat'l Vital Statistics Reports 1 (2020). https://bit.ly/CDCbirths-19.

[425] Michelle J.K. Osterman & Joyce A. Martin, *Recent Declines in Induction of Labor by Gestational Age*, Nat'l Ctr. for Health Statistics Data Brief 155. (June 2014). https://bit.ly/NCHS-14

[426]Joyce A. Martin, et al., *Births*, *supra* note 424.

[427] Mary Breheny and Christine Stephens, *Youth or Disadvantage? The Construction of Teenage Mothers in Medical Journals*, 12 Culture, Health & Sexuality 307 (2010).

[428] Melodie Cardin, *Reconsidering "Advanced Maternal Age:" Communicating About Pregnancy, Disability Risk and Ageing*, 20 Feminist Media Studies 1073 (2020).

[429] As to adolescents, *see* Courtney Everson & Bayla Ostrach, *Pathologized Bodies & Deleterious Birth Outcomes: Iatrogenic Effects of Teen Pregnancy Stigma*, *in* STIGMA SYNDEMICS: NEW DIRECTIONS IN BIOSOCIAL HEALTH 61 (Bayla Ostrach, Shir Lerman, and Merrill Singer eds., 2017). As to older parents, *see* Melodie Cardin, *Reconsidering "Advanced Maternal Age": Communicating About Pregnancy, Disability Risk and Ageing*, 20 Feminist Media Studies 1073 (2020).

[430] Christie A. Barcelos, *Producing (Potentially) Pregnant Teen Bodies: Biopower and Adolescent Pregnancy in the USA*, 24 Critical Public Health 476 (2014).

[431] Rebecca Dekker, PhD, RN, et al. *Evidence On: Pregnancy at Age 35 and Older* (2021) (noting that "*Advanced maternal age* (AMA) is usually defined as being 35 or older at the time of giving birth. Since the 1950s and possibly earlier, the age thresholds of 35 and 40 have been used by researchers to label pregnant people as being advanced maternal age.") https://bit.ly/EBB-AMA.

[432] Rosaly Correa-de-Araujo and Sung Sug (Sarah) Yoon, *Clinical Outcomes in High-Risk Pregnancies Due to Advanced Maternal Age*, 30 J. of Women's Health 160, 161 (2021).

Until the age of 18, the decisional capacity of adolescents is generally limited by the legal disabilities of minority, but the status of pregnancy creates an exception that permits minors to consent to medical care related to the pregnancy.[433] As such, the legal disability of minority is not, in the case of pregnancy, a permissible age-based distinction.[434] And yet pervasive accounts of obstetric violence among adolescents demonstrate the extent to which age-based discrimination occurs.[435]

For older parents, systemic age-based discrimination occurs more subtly: in the absence of a bright line of legal demarcation, discrimination is perpetuated through institutional policies[436] and, in some jurisdictions, administrative law.[437] Through codification of the nebulous, socially constructed AMA designation, older parents are thus subjected to age-based discrimination that has the effect of interrupting physiologic birth processes, introducing dangerous interventions with iatrogenic effects, and inducing psychosocial harms.[438]

In this climate of pervasive age-based discrimination within the perinatal care system, ample opportunity exists for OCR to protect the civil rights of individuals who access or seek to access covered health programs or activities. Even though each occurrence of age-based obstetric violence will not give rise to an actionable violation of the Age Discrimination Act, the conduct typified in the following examples demonstrates the need for OCR to utilize its authority under Section 1557 to address age discrimination in perinatal care. Although it is impossible to articulate an exhaustive list of how age-based discrimination manifests in perinatal care, the examples below are offered to illustrate common discriminatory practices.

1. Early Induction Without Consent Among Adolescents Is a Form of Age-Based Discrimination in Childbirth.

Induction pressure without explanation is one of the most concrete examples of how pregnant adolescents are systematically excluded from their own care and, as a result, denied evidence-based practices. Induction routinely occurs in the absence of informed consent as the result of providers preying on young parents' fears around childbirth and a prevailing "doctor knows best" atmosphere that dismisses the birthing person's bodily autonomy. Due to the known iatrogenic effects of induction and growing global concerns about preterm labor and low

[433] Kathryn Hickey, *Minors' Rights in Medical Decision Making*, 9 JONA's Healthcare Law, Ethics & Regul. 100,102 (2007).
[434] *See* 45 CFR § 91.2 (creating a permissible exception for age distinctions that are "established under authority of any law").
[435] Everson & Ostrach, *Pathologized Bodies & Deleterious Birth Outcomes*, *supra* note 429.
[436] Facilities and health care practices routinely deem AMA pregnancies "high risk." *See, e.g.*, SSM Health, *What is a High Risk Pregnancy?*, WWW.SSMHEALTH.COM, https://bit.ly/SSMH-highrisk (2022) (a health system that includes 23 hospitals in Illinois, Missouri, Oklahoma, and Wisconsin characterizing being "older than 35" as a "factor[] that puts moms at risk" in its marketing and patient education materials); and Marie M. Danby, MD, *Pregnancy After* 35, WWW.HATTIESBURGCLINIC.COM, https://bit.ly/HBC-35 (a clinical practice of more than 300 providers caring for patients in more than 18 counties in South Mississippi claiming that "[o]ne of the most common high-risk pregnancy factors is advanced maternal age, or pregnancy after 35" in its marketing and patient education materials).
[437] *See e.g.*, 7-13-1 ARK. CODE R. § 406.02(5) (requiring physician approval for people over age 40 to obtain midwifery care); La. Admin. Code 46:XLV.5315.B.19. (prohibiting a licensed midwife from providing care to individuals expecting their first child at or over age 40). As manifestations of the states' inherent police powers to regulate health care practitioners, age distinctions of this sort cannot be construed as aspects of a program or activity that would fall within the ambit of the exceptions to the Age Discrimination Act articulated at 45 CFR § 91.12.
[438] National Partnership for Women & Families, *Blueprint for Advancing High-Value Maternity Care Through Physiologic Childbearing*, 3-4 (2018).

birthweight, which increase with early induction, the US health and medical community has made concerted efforts to lower the early induction rate.[439,440] However, childbearing adolescents have not benefited from these concentrated efforts; in fact, between 2006 and 2013, declines in induction between 35 and 37 weeks gestation were witnessed for all maternal age groups *except* childbearing adolescents under the age of 20, who experienced a 10% *increase* in induction at 35 weeks and a 5% *increase* at 36 and 37 weeks.[441] Such trends serve as a measure by which pregnant teens—on the basis of age—are subjected to comparatively more interventions that are *not* evidence-based.

2. Limitations on Access to Midwifery Care for Older Parents Are a Form of Age-Based Discrimination in Childbirth.

An especially insidious way that age-based discrimination adversely influences access to care is the way that legal and institutional policies function to thwart access to the midwifery model of care (a form of sex-based discrimination discussed above), which supports physiologic childbirth and is shown to improve perinatal outcomes. Institutional policies frequently categorize AMA pregnancies as "high risk" by default without regard to individual markers of health, with the "high risk" categorization warranting the increased monitoring and interventions of the obstetric model of care. [442] Regulatory provisions governing the scope of midwifery practice draw similar distinctions based solely on age, prohibiting midwives from caring for individuals past a certain age.[443] In these ways, age distinctions grounded in stigma rather than evidence systematically restrict the perinatal care options available to older childbearing individuals. OCR should consider age when receiving reports related to a lack of access to care like midwifery care.

3. Coerced and Unnecessary Interventions Imposed Upon Adolescents Are a Form of Age-Based Discrimination in Childbirth.

Providers tend to approach adolescent pregnancy with a high degree of paternalism, rushing young parents through labor and seeking to exert control over every aspect of the birth process through such practices as the pervasive routine use of Pitocin in the absence of a medical

[439] Debby Amis, *Healthy Birth Practice #1: Let Labor Begin on Its Own*, 23 J. of Perinatal Educ. 178 (2014).
[440] American College of Obstetricians & Gynecologists, *Committee Opinion No. 561: Nonmedically Indicated Early-Term Deliveries*, 121 Obstetrics & Gynecology 911 (2013).
[441] Osterman & Martin, *Recent Declines in Induction of Labor by Gestational Age, supra* note 425.
[442] *See, e.g.*, SSM Health, *What is a High Risk Pregnancy?*, ssmhealth.com (2022), https://bit.ly/SSMH-highrisk (2022) (a health system that includes 23 hospitals in Illinois, Missouri, Oklahoma, and Wisconsin characterizing being "older than 35" as a "factor[] that puts moms at risk" in its marketing and patient education materials); Marie M. Danby, *Pregnancy After* 35, HATTIESBURG CLINIC (accessed June 16, 2022), https://bit.ly/HBC-35 (a clinical practice of more than 300 providers caring for patients in more than 18 counties in South Mississippi claiming that "[o]ne of the most common high-risk pregnancy factors is advanced maternal age, or pregnancy after 35" in its marketing and patient education materials). *See also* Alexa Richardson, *The Legal Infrastructure of Childbirth* 134 Harv. L. Rev. 2209, 2225 (2021) (noting that "blanket restrictions that deny people the ability to weigh individual risks and make informed decisions apply a double standard to the birthing process that is rarely present in other healthcare settings.").
[443] *See. e.g.*, 7-13-1 ARK. CODE R. § 406.02(5) (requiring physician approval for people over age 40 to obtain midwifery care); La. Admin. Code 46:XLV.5315.B.19. (prohibiting a licensed midwife from providing care to individuals expecting their first child at or over age 40). As explained above, age distinctions of this sort are neither necessary for the normal operation of a program or activity nor for any statutory objective within the meaning of 45 CFR § 91.12.

indication, artificial rupture of membranes, forced episiotomies, and vaginal exams without consent. This mistreatment leaves adolescents feeling disrespected, stripped of control, and undervalued and can contribute to a view of "childbirth as traumatic," which in turn increases the risks of both postpartum depression and posttraumatic stress, two intertwined conditions that impact bonding and long-term mental health.[444] For those who also have a history of sexual assault, as discussed above, this risk can be compounded. Epidurals are another common intervention pushed on teens in an effort to regulate labor due to provider attitudes that assume pregnant adolescents are "too selfish" and "immature" to birth without pharmacologic pain management.[445] Nationally, adolescents under the age of 20 have a 78.3% epidural use rate, the highest of any age group and another measure of age-based discrimination during care.[446] Thus dismissive attitudes combine with forced interventions to normalize discrimination on the basis of age within obstetric culture.

V. Discrimination on the Basis of Disability Is Widespread Throughout the Perinatal Period and OCR Has the Authority to Address It.

Disability-based discrimination manifests during the perinatal period and is ripe for OCR intervention under the authority granted by Section 504 of the Rehabilitation Act of 1973 (Section 504), the Americans with Disabilities Act of 1990 (ADA), and Section 1157 of the Affordable Care Act (Section 1557). Pregnant people with disabilities are at greater risk for adverse maternal health outcomes and are disproportionately harmed within the larger context of the Nation's maternal health crisis.[447] Pregnant people with disabilities are met with unique barriers such as inaccessibility and ableism when receiving pregnancy related care.[448] Moreover, pregnant people living with substance use disorder [449] (SUD) experience discrimination, stigma, and criminalization carried out by institutional policies and health care practitioner practices that disrupt bodily autonomy of the pregnant person and are inconsistent with treating substance use disorder as a disability covered under Section 504.[450] Because the provision of perinatal care to pregnant people with disabilities and non-disabled pregnant people differs "on the basis of disability," the anti-discrimination protections of Section 1557, the ADA, and Section 504 are triggered.[451]

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[444] Madeleine Simpson, et al., *Postnatal Post-Traumatic Stress: An Integrative Review*, 31 Women & Birth 367 (2018).
[445] Courtney Everson, *Structural Vulnerability and Obstetric Violence among Childbearing Adolescents in the United States: Narratives of Care, in Obstetric Violence: Realities, and Resistance from Around the World* (Castaneda, N. Hill, J. Searcy, eds., 2022).
[446] Martin, et al., *Births: Final Data for 2019, supra* note 424.
[447] Robyn Powell, *Becoming a Disabled Parent: Eliminating Access Barriers to Health Care Before, During, and after Pregnancy*, 96 Tulane L. Rev. 5–6 (2022).
[448] *Id.*
[449] Substance use disorder (SUD) occurs when the recurrent use of alcohol and/or drugs causes clinically significant impairment, including health problems, disability, and failure to meet major responsibilities at work, school, or home. *See* Substance Abuse & Mental Health Services Administration, *Mental Health and Substance Use Disorders*, SAMHSA.GOV (last updated April 30, 2020), https://www.samhsa.gov/find-help/disorders.
[450] *See* ACOG, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*, *supra* note 393.
[451] 42 U.S.C. § 18116(a). 29 U.S.C. §§ 701-796.

A. Discrimination on the Basis of Disability is Widespread in the Context of Pregnancy and Childbirth.

As a marginalized community, people with disabilities experience a range of health and health care inequities especially reproductive health care[452], despite legal protections that prohibit disability-based discrimination by health care providers.[453] These inequities disproportionately burden Black, Indigenous, and People of Color (BIPOC) with disabilities and Queer and Trans people with disabilities due to systemic racism, homophobia, and transphobia.[454] During the perinatal period, pregnant people with disabilities face healthcare inequities that translate to increased risk of complications and poorer outcomes compared to non-disabled pregnant people.[455] Pregnant people with disabilities are also more likely than those without disabilities to avoid or forego prenatal care. Further, Research suggests that providers lack education and training about treating pregnant people with disabilities, and negative interactions with health care providers may influence pregnancy decisions among pregnant people with disabilities.[456]

Accessible medical equipment is important for people with mobility disabilities, and OCR notes that medical equipment should be accessible for gynecological visits and mammography.[457] The same principle applies to perinatal care.[458] This principle also applies to other disabilities that do not impact mobility but nonetheless impact medical equipment. For example, Little People struggle to find equipment made for them, as do people whose size or weight is outside the norm for other reasons.[459]

People with disabilities also face bias and stereotypes that they cannot or should not be sexually active or reproduce.[460] As a result they face several interconnected barriers: absent or incomplete information; absent or incomplete options with regard to fertility, birth control, childbirth, lactation; paternalistic attitudes which can lead to interventions or procedures done without consent, including both sterilization and cesarean surgery; lack of communication due to inaccessible materials (not having materials for people with auditory or visual disabilities, or

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[452] Emily DiMatteo et. al. Reproductive Justice for Disabled Women: Ending Systemic Discrimination, Report for American Progress, April 2022.
[453] *See* Powell, *Becoming a Disabled Parent, supra* note 447, at 55.
[454] *Id.*, at 55.
[455] *Id.*, at 5–6.
[456] "A study of 1,000 obstetrician-gynecologists about practice accessibility, training, attitudes, and perspectives concerning treating women with disabilities also revealed substantial barriers Specifically, this study found that only 17% of obstetrician gynecologists had received information or training on providing health care to women with disabilities. Moreover, only 19% of obstetrician gynecologists felt "definitely" adequately prepared to care for pregnant women with disabilities.94 Further, more than half of obstetrician gynecologists reported difficulty communicating with patients with sensory or intellectual disabilities." Powell, *Becoming a Disabled Parent, supra* note 447, at 19 (Citation omitted).
[457] U.S. Department of Justice & U.S. Department of Health & Human Services, *Americans with Disabilities Act: Access to Medical Care for Individuals with Mobility Disabilities*, ADA.GOV (last updated February 28, 2020), https://bit.ly/3OC6Cl5.
[458] Tara Lagu et al., *Access to Subspecialty Care for Patients with Mobility Impairment: A Survey*, 158 Annals of Internal Med. 441 (2013).
[459] *See* Disability Rights Educuation & Defense Fund, *Medical Equipment: Introduction and Overarching Issues* (last visited May 13, 2022), https://bit.ly/38lhXqc.
[460] Anita Silvers, Leslie Francis, & Brittany Badesch, *Reproductive Rights and Access to Reproductive Services for Women with Disabilities*, 18 AMA Journal of Ethics 430 (2016).

people with learning or developmental disabilities)[461]; and general ignorance on the part of providers about the reproductive abilities and needs of pregnant and birthing people with disabilities.[462] One stark example of this mistreatment was the case of Angela Carder who was court ordered to have a cesarean surgery even though, given that she was living with cancer, the surgery could shorten her life. A D.C. Appeals Court overturned the court ordered cesarean surgery, but only after she and her newborn had died.[463]

It is also not uncommon for people to face scorn and judgment related to their decision to reproduce while being a person with a disability and to then face disparate treatment as a result. People with disabilities experience disproportionate involvement from the state when they become parents, which can include removal of infants at birth.[464] This is particularly common for birthing people with substance use disorder (SUD) who are uniquely subject to punitive policies and heightened criminalization.

Criminalization of pregnancy occurs when pregnant people are punished for actions that are interpreted as harmful to their own pregnancies, including policies that penalize pregnant people for substance use during pregnancy.[465] BIPOC communities are disproportionately harmed by punitive responses to substance use, despite their rates of drug use being comparable to white people as explored in more detail above.[466]

B. OCR Can and Should Use Its Authority to Address Discrimination on the Basis of Disability In the Context of Perinatal Health.

When disability limits the available care options or influences the way care is delivered, discrimination occurs. Despite federal disability rights laws that prohibit disability-based discrimination by health care providers, people with disabilities experience numerous health care inequities. These inequities are addressed with regard to many forms of health care already but need to be addressed in the context of perinatal care, and especially in the context of childbirth and the postpartum period.

Protections against disability-based discrimination in health care is governed by three major federal laws: Section 504 of the Rehabilitation Act of 1973 (Section 504), the Americans with Disabilities Act of 1990 (ADA), and the Patient Protection and Affordable Care Act (ACA).[467] Pursuant to Section 504, entities receiving federal funds are required to provide equal access to programs and services for people with disabilities.[3] As most health care facilities and providers receive federal funding through Medicare, Medicaid, and federal block grants, Section 504 is crucial and makes explicit, "No otherwise qualified individual with a disability in the United States shall, solely by reason of her or his disability be . . . be subject to discrimination

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[461] Office for Civil Rights, *Voluntary Resolution Agreement: Rhode Island Department of Children, Youth, and Families*, HHS.GOV (Mar. 25, 2022), https://bit.ly/3MZy8HJ.
[462] Silvers, Francis & Badesch, *Reproductive Rights and Access to Reproductive Services for Women with Disabilities*, *supra* note 460.
[463] *In re A.C.*, 573 A.2d 1235, 1240-41 (1990).
[464] National Council on Disability, *Rocking the Cradle*, *supra* note 67.
[465] ACOG, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*, *supra* note 393.
[466] *See* LAC, *Re: Comments on Notice of Proposed Rulemaking for RIN 0945-AA00* 8 (May 6, 2021), https://bit.ly/3aV5sCo.
[467] Office for Civil Rights, *Fact Sheet: Drug Addiction and Federal Disability Rights Laws*, HHS.GOV (Oct. 25, 2018), https://bit.ly/3N84el4 (hereinafter "OCR, Fact Sheet: Drug Addiction & Federal Disability Rights Law"].

under any program or activity receiving Federal financial assistance…"[468] The ADA aims to ensure people with disabilities do not experience discrimination in health care settings and provides enforceable standards to address such discrimination. Finally, Section 1557 of the ACA prohibits disability-based discrimination by health care providers that receive federal funding, and grants OCR authority to enforce this requirement.[469]

It is important that all three of these laws are leveraged to address discrimination on the basis of disability in the context of perinatal health, because disability manifests in so many different ways and will intersect with pregnancy and birth in a wide variety of ways. Disability during pregnancy is as diverse as the people who are pregnant.

1. Disparate Treatment Based on One's Experience of Substance Use Disorder (SUD) is Discrimination on the Basis of Disability Under Federal Civil Rights Law.

It is particularly important to recognize that substance use disorder is covered as a disability under Section 504. Section 504 defines individuals with disabilities as persons with a physical or mental health impairment which substantially limits one or more major life activities. Notably, alcoholism and drug addiction are impairments covered under the law. Section 504 further specifies: "People who have a history of, or who are regarded as having a physical or mental impairment that substantially limits one or more major life activities, are also covered." When substance use substantially limits a major life activity, it is considered a disability under the Americans with Disabilities Act (ADA) and Section 1557 of the Affordable Care Act (ACA).[470] This is particularly important because of the discrimination and mistreatment people experiencing a use disorder face during pregnancy.

These federal protections extend to individuals who have completed, or are participating in, a drug rehabilitation program and are currently not engaged in the use of illegal substances, as well as those who are inaccurately regarded as engaging in the use of illicit substances.[471] This means that these protections extend to people who use medication assisted treatment like Methadone or Suboxone during pregnancy, which will show up as opioids in drug tests of the pregnant person and their newborn and will be indistinguishable from opioids that are not prescribed.

In this climate of pervasive disability-based discrimination within the perinatal care system, ample opportunity exists for OCR to protect the civil rights of individuals who access or seek to access covered health programs or activities. The conduct typified in the following examples demonstrates the need for OCR to utilize its authority under Section 504, the ADA, and Section 1557 to address disability-based discrimination in perinatal care. The examples below provide insight into recurrent discriminatory experiences faced by pregnant and parenting people with or suspected of having substance use disorder (SUD).

(a) Having a SUD or Suspected SUD Increases Risk of Unlawful Discrimination During the Perinatal Period.

[468] Powell, *Becoming a Disabled Parent, supra* note 447, at 9.
[469] *See id.* at 11,13.
[470] OCR, *Fact Sheet: Drug Addiction & Federal Disability Rights Law*, *supra* note 467.
[471] 29 U.S.C. § 705(20)(C)(ii); 42 U.S.C. § 12210(b).

Pregnant people with SUD are particularly vulnerable to mistreatment and abuse when giving birth.[472] Pregnant people who self-disclose use of illicit substances or test positive for them may be subjected to degrading or stigmatizing comments, and unsubstantiated assumptions that their substance use will directly correlate to negative birth outcomes.[473] However, research on pregnant people who use drugs cannot state if one behavior results in a negative outcome.[474] Studies on pregnancy and substance use fail to control other variables such as poverty and racism that contribute to unfavorable health outcomes.[475]

(b) Drug Testing Without Informed Consent and Reporting to Child Protective Services Is a Form of Unlawful Discrimination.

In the absence of universal screening, disability-based discrimination occurs as folks with a history of substance use disorder or suspected of substance use disorder are disproportionately screened and tested for illicit substances. Pregnant and postpartum people with substance use disorder and their newborn babies are typically drug tested in medical settings without their knowledge or explicit informed consent.[476] Drug testing without informed consent undermines the doctor-patient relationship, violates medical ethics, and can deter pregnant people from obtaining prenatal and other healthcare during pregnancy.[477]

Institutional policies and practices that use substance use screening tests as an indicator of child abuse, which results in reporting to child protective services, are inconsistent with treating substance use disorder as a health condition and fail to account for inaccurate results, also referred to as a false positive.[478] False positives may occur in two situations: when the chemical compound is not present at all or when the chemical compound is present but comes from a lawful source, like medication, which may be referred to as "partially false positive."[479] The test result does not distinguish between a positive for criminalized opioids, such as heroin, and non-criminalized opioids such as prescribed pain killers and the treatment medications such as methadone. Lawsuits or ethical complaints have been filed in New York, California, Alabama, Maryland, and a handful of other states over the past decade after mothers say they received unconfirmed or false positive results from eating poppy seed bagels or salad dressing, taking doctor-approved Valium, and using prescribed asthma inhalers.[480] In fact, the U.S. Department of Justice has explained, "A positive test result, even when confirmed, only indicates that a particular substance is present in the test subject's tissue. It does not indicate abuse or addiction, recency, frequency, or amount of use; or impairment."[481] Therefore, a positive clinical drug test

[472] If/When/How, *Report to the U.N. Special Rapporteur on Violence Against Women* 9 (May 17, 2019), https://bit.ly/3mUtsZb [hereinafter "If/When/How, *Report to the U.N."*].
[473] *See* National Harm Reduction Coalition & Academy of Perinatal Harm Reduction, *Pregnancy and Substance Use: A Harm Reduction Toolkit* 2, 7 (2020).
[474] *Id.*
[475] *Id.* at 16.
[476] *See* National Advocates for Pregnant Women, *Clinical Drug Testing of Pregnant Women and Newborns*, at 1 (2019), https://bit.ly/3P9V9cq.
[477] *Id.* at 2.
[478] ACOG, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*, *supra* note 393, at 9.
[479] NAPW, *Clinical Drug Testing of Pregnant Women and Newborns*, *supra* note 476 at 1–2.
[480] Claudia Lauer, *Mother Sues Hospital Over Drug Test That Led to Abuse Probe*, ABC NEWS (Mar. 11, 2020), https://abcn.ws/3Nlll3b.
[481] Birth Rights Bar Association, *Birth Rights: A Resource for Everyday People to Defend Human Rights During Labor and Birth*, at 18 (2020), https://bit.ly/3b09nOl [hereinafter BRBA, *Birth Rights*].

does not prove the patient was using a particular substance because many clinical test results are not reliable and are not forensic evidence.[482]

For example, Melissa McCann Arms was reported to law enforcement by health care personnel who judged her to be acting "erratically" as she struggled to cope with her labor.[483] A nurse treating Ms. Arms called police and told them that she suspected her patient was under the influence of controlled substances, even though such reporting is not required by law and medical ethics forbid disclosing confidential patient information.[484] While Ms. Arms was still in active labor, police officers presented her with a warrant for the collection of biological samples to test for criminalized drugs.[485] She was questioned at her hospital bedside shortly after delivery and was accused by police of having harmed her baby when she admitted to having used a criminalized drug at an earlier point in her pregnancy. Ms. Arms' ordeal continued far beyond her experience of disrespectful care at birth. Although she completed drug treatment and counseling and the state child welfare authority approved reunification with her child, she was charged with a poisoning crime (introducing a controlled substance into the body of another person). She was sentenced by a jury to 20 years in prison and had already served part of her sentence by the time the state high court overturned the conviction. Ms. Arms was vindicated by the court, but she and her child suffered irreparable harm from the humiliation of a police investigation and her subsequent arrest.[486]

Additionally, drug testing without informed consent not only manifests as disability-based discrimination but also contributes to race-based discrimination, as current policies and practices are often applied selectively, disproportionately impacting poor people and people of color.[487] A study on the effect of race on provider decisions to test for illicit drug use found, "Black women and their newborns were 1.5 times more likely to be tested for illicit drugs as nonblack women in multivariable analysis…[though] We found equivalent positivity rates among tested black and nonblack women."[488] Selection bias in testing results in disproportionate screening and testing of low-income patients and patients of color and results in the reporting of Black parents at higher rates to welfare authorities by obstetricians suspecting illicit prenatal drug use. Moreover, racial discrimination in healthcare manifests in lack of treatment as well, for instance, Black and Latine/x people are 60-75% less likely to receive medication to treat their opioid use disorder (OUD) during pregnancy.[489]

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[482] "Examples from across the U.S. and abroad demonstrate the risks of contamination in laboratories and the resulting errors in test results and reporting. For example, between 2005 and 2015, the Motherisk Laboratory at the Hospital for Sick Children in Toronto tested more than 24,000 hair samples for drugs and alcohol, from over 16,000 different individuals, for child protection purposes. The results were introduced as evidence in court and resulted in both temporary and permanent loss of custody of children. An independent review in 2015 found this testing was "inadequate and unreliable" for use in child protection and criminal proceedings." BRBA, *Birth Rights, supra* note 481 at 20.

[483] Jeri Peason, *Arms Receives Maximum Sentence for Taking Controlled Substances While Pregnant*, MYPULSENEWS.COM (Jan. 14, 2014), https://bit.ly/3NdxXcq.

[484] *Id.*

[485] *Id.*

[486] If/When/How, *Report to the U.N., supra* note 472, at 9–10.

[487] BRBA, *Birth Rights, supra* note 481 at 18.

[488] American Bar Association, *Child Welfare Court Cases Involving Prenatal Substance Use: Policy Considerations*, at 6 (2021).

[489] Caroline Le & Sarah Coombs, *Substance Use Disorder Hurts Moms and Babies*, NAT'L PARTNERSHIP FOR WOMEN & FAMILIES (2021), https://bit.ly/3zYOwpl.

C. Extreme and Punitive Policies Are Increasing and OCR Should Act to Restrict Such Harmful Actions.

From 2000 to 2015, the number of states with punitive policies and requirements for health professionals to report suspected prenatal drug use doubled as did the incidence of parental alcohol and other drug use as a contributing factor for child removal between 2000 and 2016, going from 18% to 35%, and 17.5% of those children were under the age of one.[490] A punitive approach to SUD causes poor health outcomes, such as higher rates of neonatal abstinence syndrome (NAS)– a drug withdrawal syndrome that occurs after infants are exposed to certain drugs in utero.[491] The criminalization of substance use during pregnancy drives fears in pregnant people, resulting in fewer pregnant people with SUD seeking prenatal care and drug treatment, which can endanger the health and well-being of pregnant people, infants, and their families. Instead, interventions including breastfeeding, and remaining in close contact with the newborn rather than removal by child protective services reduce the need for pharmacotherapy for newborns with NAS.[492]

Child removal at birth, whether it be due to a real or perceived disability, or discrimination on the basis of race, sex, or age, is an extreme and traumatic intervention that requires participation from health systems, facilities, providers and the state. Punitive policies and practices, such as "test and report" (outlined above), are particularly common in the context of substance use and pregnancy and has harmful consequences for the pregnant person and newborn.[493] Child custody loss associated with substance use disorder has negative health implications for parents, including acute, immediate psychosocial crisis and increased drug use.[494]

Federal anti-discrimination protections, including the ADA, Section 1557, and Section 504, should ensure pregnant and parenting people with disabilities have adequate access to health care.[495] Notwithstanding many people with disabilities experience significant barriers when accessing health care during the perinatal period. Whereas such barriers indicate a need for greater compliance with, enforcement of, and education about federal disability rights law. Addressing disability-based discrimination and obstetric racism and violence must occur within healthcare institutions, and the federal government is uniquely positioned to take swift and comprehensive action vis-a'-vis HHS's OCR.[496] Through its Section 1557 authority, OCR should immediately begin processing complaints and conducting investigations on individual reports of discrimination.

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[490] Alexandra Punch, *Pregnant Women with Substance Use Disorders Deserve Plans of Safe Care*, LERNER CTR. (June 15, 2021), https://bit.ly/3xAHRyy.
[491] Le & Coombs, *Substance Use Disorder Hurts Moms and Babies, supra* note 489.
[492] Karen McQueen, Carleigh Taylor & Jodie Murphy-Oikonen, *Systematic Review of Newborn Feeding Method and Outcomes Related to Neonatal Abstinence Syndrome*, 48 J. Obstetric, Gynecological & Neonatal Nursing 398 (2019).
[493] American Civil Liberties Union, *Ferguson v. City of Charleston: Social and Legal Contexts*, ACLU.ORG (Oct. 4, 2000), https://bit.ly/3Pklbe7**.**
[494] Laura Lander, Janie Howsare & Marilyn Byrne, *The Impact of Substance Use Disorder on Families and Children: From Theory to Practice*, 28 Soc. Work Pub. Health 194 (2013).
[495] Powell, *Becoming a Disabled Parent, supra* note 447 at 44.
[496] *Id.*

VI. Recommendations

Combatting discrimination, obstetric racism and obstetric violence must occur within institutionalized spaces of biomedical care and OCR is uniquely poised to ensure that this takes place. Through its Section 1557 authority, OCR should immediately begin processing complaints and conducting investigations on individual reports of discrimination. In addition to reviewing individual complaints there are a number of different ways in which OCR could work to reduce the prevalence of, and improve accountability for, obstetric racism and obstetric violence. This section offers a series of recommendations for specific ways in which OCR could approach this endeavor.

A. *Bowen v. American Hosp. Association* is Instructive and Supports Expanded Responsiveness to Obstetric Racism and Obstetric Violence.

The decision in *Bowen* stems from final rules promulgated by the Secretary of the Department of Health and Human Services which would have created a comprehensive response to "unlawful medical neglect of handicapped infants."[497] The rules contemplated a "vigorous federal role."[498] The Department could not ultimately proceed with this comprehensive response since the Court determined that the four mandatory provisions of the plan were not authorized by the Rehabilitation Act. Those four mandatory provisions included posting of notices, requiring state CPS involvement, expedited access to records, and expedited compliance actions.[499]

Two important factors in that case distinguish it from the issues presented by obstetric racism and obstetric violence. First, the administrative response to "unlawful medical neglect of handicapped infants" was in conflict with informed consent (it did not acknowledge the role of informed consent in medical decision making for these infants, and it did not acknowledge the role of parents as the bearers of the decision-making authority for their infants).[500] Second, the administrative response was not consistently well grounded in evidence of discrimination against these infants (there was a lack of evidence of discrimination, and discrimination was not articulated as a foundation for the requirements).[501]

In contrast, the response requested to address obstetric racism and obstetric violence is grounded in informed consent, aligns with existing law, and seeks equal protection of those laws for people in the perinatal period. The response requested here is free from the complications of delegated decision-making that hampered the Department with regard to medical decision-making for infants.[502] Here there are only competent individuals making their own health care decisions, although their ability to make those decisions is often hampered by a desire for delegated decision-making for fetuses that is not legally supported (and was the problem in *Bowen*) . Indeed, the desire for delegated decision-making for fetuses is grounded in discriminatory distrust of pregnant people as decision-makers. The fact that *Bowen* establishes that "Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions," affirms this

[497] Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986).
[498] *Id.* at 618.
[499] *See id.* at 614-618.
[500] *Id.* at 619.
[501] *Id.* at 624.
[502] *See id.* at 627-630.

brief's position. Unsolicited advice systematically delivered by hospitals and state officials to coerce pregnant and laboring people in their individual treatment decisions may be a form of discrimination giving rise to a "colorable basis for believing that a violation of §504 had occurred or was about to occur."[503]

Indeed, a problem with the agency's efforts to protect these infants was their use of State agencies to enforce compliance with DHHS rules. *Bowen* firmly establishes that state agencies cannot be conscripted "as the foot soldiers in a federal crusade."[504] However, *Bowen* is equally clear that "The Secretary can require state agencies to document their own compliance with §504,"[505] which is more relevant to these issues where a common form of discrimination is the use of state agencies to remove newborns from their families.

Furthermore, this brief establishes evidence of discrimination and requests that it be articulated as the basis for OCR's response. *Bowen* maintains that "a hospital rule or state policy denying or limiting" an infant's access to benefits would be subject to challenge under the Rehabilitation Act.[506] But the agency relied on forty-nine "infant Doe cases" and none of them "resulted in a finding of discriminatory withholding of medical care."[507] The Court found the agency's evidentiary basis for its rules lacked sufficient connection to discrimination and that there was insufficient support for federal intervention. "The Secretary's basis for federal intervention is perceived discrimination against handicapped infants in violation of §504 and yet the Secretary has pointed to no evidence that such discrimination occurs."[508] In contrast, this brief describes a range of benefits that pregnant and laboring people are regularly denied access to as a result of hospital rules and practices, and asks OCR to use its existing investigative authority to identify discrimination, not act in the absence of evidence of discrimination.

The issues presented during pregnancy and birth across multiple dimensions of discrimination within OCR's purview suggest the need for a "vigorous federal role" which could certainly be designed to fit within the constraints of statutory authority and legal precedent.

B. Cooperation and Assistance, Compliance Reports, Access to Sources of Information

OCR has the authority to require its grantees to cooperate with its guidance surrounding non-discrimination in healthcare. It can monitor this cooperation through compliance reports that would provide a useful source of accountability for healthcare providers nation-wide. The following section will provide an overview of some useful, existing, measurement tools that could be mobilized towards this end.

1. <u>Suggest Use of Patient Experience Measures Like the Patient Reported Experience Measure of Obstetric Racism© (The PREM-OB Scale™ Suite), the Mothers on Respect Index, the Mothers Autonomy in Decision Making Scale.</u>

Until very recently in the US there has been little recognition of the extent and impact of these problems, lack of consensus on how to measure them, and few mechanisms for transparency, accountability, or effective recourse when harms occur. However, new

[503] Bowen v. Am. Hosp. Ass'n, 476 U.S. 610, 647 (1986).
[504] *Id.* at 642.
[505] *Id.*
[506] *Id.* at 624.
[507] *Id.* at 634.
[508] *Id.* at 643.

measurement tools have emerged over the last several years and OCR should require its grantees to use them.

In 2016, for example, the World Health Organization (WHO) published eight standards for assessment of quality of maternal and newborn care including "the extent to which health care services provided to individuals and patient populations improve desired health outcomes and [are] safe, effective, timely, efficient, equitable and people-centered."[509] Earlier, in 2015, Bohren and colleagues (2015) published findings from a systematic review of 65 studies on experience of care during childbirth across 34 countries and a variety of geographic and economic contexts. The investigators reported widespread disrespect and human rights violations experienced by birthing people.[510] Citing a wide range of definitions and descriptors of disrespect and abuse, they created a consistent typology for assessing prevalence of mistreatment: physical and verbal abuse, neglect, stigma and discrimination, denial of autonomy, health system deficits, and failure to provide emotional support.[511]

The WHO subsequently affirmed that the ability for self-determination, participation in decision-making, and freedom from discrimination, harm and mistreatment are human rights, are independent, and important health outcomes that should be measurable and evaluated at the service provision level.[512] Despite these realities, to date, there are minimal accountability mechanisms that capture and account for the complex lived experiences of mistreatment during the core and formative life experiences of pregnancy and birth.[513]

Spurred by increased demand for person-centered, rights-based metrics, researchers at the Birth Place Lab developed and validated three new scales, the Mothers Autonomy in Decision Making (MADM) and the Mothers on Respect (MOR) index, and a Mistreatment (MIST) index. These scales were applied in the national, community based participatory study, Giving Voice to Mothers, to assess experiences of pregnancy and childbirth care among communities of color and among those who chose community birth (home and birth centers) over hospital care. The survey captured information on the process of decision-making and autonomy when offered interventions, factors associated with mistreatment, discrimination and/or disrespect, and what happens when patients decline interventions and/or procedures. Over 17% of the total 2700 participants across all 50 states experienced some sort of mistreatment, 44% of women reported coercion, and unconsented obstetric procedures, and 30% experienced pressure to accept interventions during perinatal care. Black and Indigenous women were two to three times more likely to report pressure and that procedures were done without their consent. Of those patients who had a difference of opinion about the right care for themselves or their baby, 79% reported mistreatment and non-consented procedures and interventions.[514] Pressure to accept cesarean

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[509] World Health Organization, *Standards for Improving Maternal and Newborn Care in Health Facilities*, at 14 (2016).
[510] *See* Bohren et al., *"By Slapping their Laps, the Patient will Know That You Truly Care for Her," supra* note 43.
[511] Meghan A Bohren, et al., *How Women Are Treated During Facility-Based Childbirth in Four Countries: A Cross-Sectional Study with Labour Observations and Community-Based Surveys*, 6736 The Lancet 1 (2019)
[512] World Health Organization, *Human Rights & Health*, WHO.ORG (Dec. 29, 2017), https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health.
[513] Rajat Khosla, et al., *International Human Rights and the Mistreatment of Women During Childbirth,* 18 Health & Hum. Rights J.131 (2016); Christina Zampas, et al., *Operationalizing a Human Rights-Based Approach to Address Mistreatment Among Women During Childbirth*, 22 Health & Hum. Rights J. 251 (2020); Caitlin R. Williams & Benjamin Mason Meier, *Ending the Abuse: The Human Rights Implications of Obstetric Violence and the Promise of Rights-Based Policy to Realise Respectful Maternity Care*, 27 Sexual & Reprod. Health Matters 1 (2019).
[514] Vedam et al., *Giving Voice to Mothers Study*, *supra* note 10.

sections was associated with significantly lower autonomy (MADM) and respect (MORi) scores, and more adverse postpartum mental health outcomes.

Most recently, in 2021, the PREM-OB Scale™ Suite, developed and owned by Dr. Karen A. Scott, MD, MPH, FACOG, became the first and only perinatal instrument designed for, by, and with Black women and people, that consists of three independent scales that simultaneously measure patient experiences of violations and protections during childbirth hospitalization called: Humanity, Kinship, and Racism. Dr. Scott designed the directionality of each scale to be consistent with the key goal of measuring obstetric racism. Each scale is scored such that each item is added together to generate a summative score. The higher the score, the greater the amount or number of patient-reported experiences of obstetric racism.

The PREM-OB Scale™ Suite also serves a dual purpose: a Black woman-person focused QI metric that yields a systems level diagnosis of obstetric racism using three independent patient-driven measures plus an interpretative tool to excavate the presence and permeation of obstetric racism in any free text that characterizes clinical encounters. By selecting the text as the unit of analysis, the definitions of the domains and subdomains measured by The PREM-OB Scale™ Suite are mapped onto the patient narratives of care.

Ideally, patient-reported outcomes would also be integrated into electronic health records.

C. Provide Information to Grantees and Beneficiaries

In addition to mandating that grantees track and measure patient satisfaction and outcomes throughout the perinatal period, OCR can provide useful guidance on informed consent and refusal, as well as information about one's fundamental rights during childbirth to both grantees and beneficiaries alike.

1. <u>Issue and Disseminate Clarifying Guidance on Informed Consent and Refusal During Childbirth.</u>

OCR could take significant action to protect the civil rights of people giving birth in the U.S. by issuing a memorandum to state medical and nursing boards, the Joint Commission, and all recipients of federal funds, declaring that informed consent and refusal applies in pregnancy and childbirth, and that the rights of pregnant patients must be protected through meaningful accountability mechanisms for their violation. The violation of pregnant patients' right to informed consent is currently endemic, both through "c-section only" policies that put doctors and nurses in the position of having to coerce and force patients into surgery without informed consent, as well as individual instances of obstetric violence or obstetric racism that occur as a result of the belief among obstetric providers that pregnant patients who question their recommendations for intervention can be coerced, threatened, or forced into compliance. OCR has the authority to help recalibrate current dysfunctions in U.S. maternity care in a way that protects pregnant patients' physical and mental health, simply by ensuring that the right of informed consent during pregnancy and childbirth is recognized and protected by licensing bodies, the Joint Commission, and the institutions that provide healthcare to pregnant patients nationwide.

2. Issue Clarifying Guidance on How the Nondiscrimination Protections that OCR Enforces Apply in the Context of Pregnancy and Childbirth.

Moreover, informational guidance on issues intersecting with each form of discrimination in perinatal care would be especially impactful in educating beneficiaries about their rights. Accordingly, we urge HHS OCR to issue guidance clarifying that hospitals violate Section 1557 when they single out perinatal patients for drug tests.

Furthermore, there is significant variance between jurisdictions on issues such as when midwifery care is or is not available to "advanced maternal age" pregnancies and what exceptions to medical decision-making exist for pregnant minors. Guidance on issues intersecting with age discrimination is called for in order to adequately inform pregnant people of their care options and their rights. Greater knowledge of the existing protections against discrimination would, in turn, lead to more complaints and investigations which could ultimately result in reducing the incidence of discrimination in perinatal care.

In addition, OCR should issue joint technical assistance for health care providers on accessible health care during the perinatal period. This guidance should address health care providers' legal obligations pursuant to Section 1557. Such guidance should explain federal disability rights laws and the statutes' application as well as provide additional resources for further information. The technical assistance should be widely disseminated to health care providers and disability rights advocates and attorneys.

3. Disseminate Accessible Know-Your-Rights Information Directly to Beneficiaries.

We further urge OCR to publish Know Your Rights materials. To maximize its impact, OCR should utilize its ability to require covered health programs and activities to disseminate information to beneficiaries about their rights under the discrimination laws it enforces. Because violence in this context is so culturally accepted, individuals who have been subjected to discrimination in perinatal care are likely unaware of the civil rights afforded to them.

This could look like OCR requiring covered facilities to post a pregnancy and birth "bill of rights" in labor and delivery rooms. This could also look like OCR developing a patient-oriented platform on its website for learning about obstetric racism and obstetric violence as forms of discrimination. Increased knowledge of the existing protections against discrimination in perinatal health would, in turn, lead to more complaints and investigations which could ultimately result in reducing the incidence of discrimination in perinatal care.

Know Your Rights materials have been developed by non-profit advocacy organizations based on key legal principles but are not connected to clear pathways for accountability, much less OCR's individual complaint form.[515] Ideally, such materials would describe both rights and how to address violation of those rights in a meaningful way. Of course, such materials should also include information for perinatal patients who face nonconsensual drug tests including that they have a right to file an administrative complaint with OCR.

Such administrative complaints can lead to OCR investigations that determine whether hospitals have a broader policy or practice of discrimination, and if so, require hospitals to institute remedial measures.

[515] Birth Rights Bar Association & National Advocates for Pregnant Women, *Birth Rights: A Resource for Everyday People to Defend Human Rights During Labor and Birth* (2020), https://bit.ly/3uuCcJK; National Partnership for Women and Families, *The Rights of Childbearing Women* (2018), https://bit.ly/3yGqfCb; White Ribbon Alliance, *Respectful Maternity Care Charter, Universal Rights of Women and Newborns* (2019), https://bit.ly/3v03A2n.

D. Update Processes for Receiving Complaints.

Although the existing portal for processing discrimination complaints to OCR is a very useful and straightforward tool, there are a number of different ways in which it could better meet the needs of survivors of obstetric racism and obstetric violence.

1. Create a Separate Portal for Complaints Related to Obstetric Violence and Obstetric Racism.

As discussed above, obstetric racism and obstetric violence are so pervasive that it can be hard for people who are impacted to understand their experience as one of discrimination. As a result, OCR's existing portal for making complaints may be a deterrent for people with valid claims.

In addition, people reporting mistreatment during the perinatal period often also experience a violation of information privacy that may be covered by HIPAA. For example, information derived from unconsented drug tests may be shared with people outside of the health system and for purposes not related to health care.

OCR should consider ways to address this including the possibility of creating a separate portal specifically for discrimination during the perinatal period. This could make the portal more accessible to people and could allow OCR to consider both discrimination and HIPAA violations that may arise from the same set of facts.

2. Expand the Time Allowed for Making a Report Without Needing to Show "Good Cause."

OCR currently requests that complaints be filed within 180 days of when the victim knew the act or omission complained of occurred.[516] People filing complaints related to childbirth will by definition be in the postpartum period during that time period. The physiologic changes of the postpartum period can last at least six months, with some changes being permanent. Twelve-percent of pregnancy-related deaths occur after six weeks postpartum with some occurring later in the first year. Postpartum mental health symptoms may not arise until 12 months after birth and could last years. If the person experienced trauma during the process, it is all the more likely that symptoms will be acute beyond 180 days. It can take some months before people process their experiences enough to realize that what happened to them was violence/abuse/discrimination.[517] Not to mention the fact that many people who need to make a complaint will also be taking care of a newborn. As a result, people making these complaints will regularly need more than 180 days. Advocacy organizations have found that two-to-three years postpartum is a more achievable time period that does not add unnecessarily to postpartum stress.

[516] Office for Civil Rights, *How to File a Civil Rights Complaint*, HHS.GOV. (last accessed June 15, 2022), https://bit.ly/3OmapT8.

[517] *See e.g.* Bohren et al., *supra* note 43; Malena Correa, et al., *Observations and Reports of Incidents of How Birthing Persons Are Treated During Childbirth in Two Public Facilities in Argentina*, 158 INT'L J. OF Gynecology & Obstetrics 1 (2021).

Conclusion

Discrimination on the basis of race,[518] color,[519] national origin,[520] sex,[521] age,[522] or disability[523] while participating in any health program or activity, any part of which is receiving federal financial assistance, is prohibited.[524] OCR also has enforcement authority with respect to a vast array of health programs and activities reaching the majority of pregnant people and infants in the United States.[525] This means that any acts of discrimination that are prohibited under Section 1557 may be investigated and addressed by OCR so long as they occur in any of the healthcare settings enumerated. Tragically, such discrimination is deeply entrenched and widespread. The need for systematic accountability is great and OCR is uniquely positioned to address this need. OCR should immediately begin processing complaints and conducting investigations on individual reports of discrimination while also working prevent and to reduce the prevalence of these harms in collaboration with experts in the field, including the following experts. We look forward to partnering with you to eradicate this discrimination.

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[518] Section 1557 of 42 USC 18116 prohibits discrimination on the grounds prohibited under Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d et seq. (race, color and national origin). *See* Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority, 85 Fed. Reg. 37160 (June 19, 2020).
[519] *Id.*
[520] *Id.*
[521] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of sex, as defined under Title IX of the Education Amendments of 1972, 20 U.S.C. 1681 et seq., which encompasses discrimination on the basis of pregnancy status. *See* U.S. Dept. of Educ., *Sex Discrimination: Overview of the Law*, (last accessed Sept. 3, 2021), https://www2.ed.gov/policy/rights/guid/ocr/sexoverview.html.
[522] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of age, as defined under the Age Discrimination Act of 1975, 42 U.S.C. 6101 et seq.
[523] Section 1557 of 42 USC 18116 prohibits discrimination on the basis of disability, as defined under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794. *See* Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority, 85 Fed. Reg. 37160 (June 19, 2020).
[524] *See* Office for Civil Rights, *Discrimination on the Basis of Sex*, (last reviewed Apr. 1, 2022), https://bit.ly/3NJ3xzr.
[525] *See* Health Resources and Services Administration, *Title V Maternal and Child Health (MCH) Block Grant*, HHS.GOV (Dec. 1, 2020), https://bit.ly/3QKztFA.