# BIRT5

A Resource for Everyday People to Defend Human Rights During Pregnancy and Birth



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# How to use this guide:



A new definition, tool or naming that expands our understanding of birth justice and the work of our movements - *which include you!* 



Living into our commitment to center pregnant people in meaningful ways - and ways to support that in language and action.



Forward motion demands transformation. This guide is about us taking action together. When you see this icon, it's a *call to action*.

Forward motion



# "What you can see is actually enough."

Alexis Pauline Gumbs, excerpted from "Birth Chorus," in Dub: Finding Ceremony

# **About this Resource**

At no point in pregnancy do people lose their civil and human rights. Yet all over the world, people often experience mistreatment and violations of their rights during pregnancy, whether they experience a pregnancy loss, seek an abortion, or continue to birth.<sup>1</sup> This reality is particularly present in the United States. In fact, in August 2023, the Centers for Disease Control (CDC) released a report confirming that "one in 5 women report mistreatment while receiving maternity care" with that rate being higher for people of color.<sup>2</sup>

Doulas and other people who support pregnant and birthing people often bear witness to rights violations of clients or loved ones. In a 2018 survey, 65% of doulas and nurses indicated they had witnessed providers "occasionally" or "often" engage in procedures explicitly against their patients' wishes.<sup>3</sup> Rights violations and mistreatment in childbirth take many different forms, including violations of the rights to privacy, bodily autonomy, and medical decision-making. These violations can take place during the provision of health care through neglect, coercion, verbal abuse, forced interventions, or surgeries; when health care providers unlawfully disclose confidential health information to law enforcement or to state agencies that coordinate with law enforcement or the family policing system; and when incarcerated pregnant people are denied access to health care. The violations occur in the context of a U.S. health care system under which extreme disparities persist for Indigenous and Black women in particular,<sup>4</sup> maternal mortality is rising,<sup>5</sup> and some interventions are overused while other effective options are underused.<sup>6</sup>

Following the *Dobbs v. Jackson Women's Health Organization*<sup>7</sup> in June 2022, the importance of birth justice has only become more obvious. Abundant evidence demonstrates that states with restrictive abortion policies tend to have higher maternal mortality rates. Reporting has recently emerged identifying abortion bans as causes of death in Texas and Georgia.<sup>8</sup> Abortion restrictions overall broadly affect obstetric outcomes, especially for marginalized populations that already experience poor obstetric care and outcomes. For example, one study found that Black pregnant individuals are more likely to experience adverse birth outcomes (e.g. preterm birth and low birth weight infants) when they live in regions with more abortion restrictions.<sup>9</sup> A different study determined that "maternal death rates were 62 percent higher in 2020 in abortion-restriction states than in abortion-access states (28.8 vs. 17.8 per 100,000 births)."<sup>10</sup> Moreover, states with more abortion restrictions also tend to invest fewer resources to support pregnant individuals and their families.<sup>11</sup> This combination of restrictive access to health care services, the fear of criminalization, and limited state investment for families and children creates discriminatory and dangerous circumstances for pregnant individuals.

Because the *Dobbs* decision has shifted the landscape significantly, and as maternal mortality and morbidity continues to worsen, it was necessary to update this guide, originally published in 2020, to provide additional information and resources to pregnant individuals, families members, health care providers, and advocates. This includes additional information about racism in medical and obstetric care, and additional guidance about how to file civil and human rights complaints after a violation. Pregnancy Justice, Elephant Circle and Birth Justice Bar (BJB) created this resource with the goal of **affirming and advocating for the human rights of pregnant people in the United States,** as well as to provide concrete tools for pregnant people, doulas, partners, family members, and friends. The resource was inspired by our work with countless pregnant people, doulas, and other folks offering support to birthing people who had either experienced or witnessed violations during childbirth. Many folks have reached out to us for more information about their rights or the rights of their clients during childbirth; we have heard resounding feedback calling for more advocacy tools both to identify these rights and promote their observance, as well as more accessible information about avenues for redress of harm after it has occurred.

Pregnancy Justice and Birth Justice Bar are non-profit legal advocacy organizations committed to the human rights of pregnant and birthing people; consequently, many of the resources here are informed by legal, reproductive justice, and human rights frameworks. We recognize that there is no definitive strategy that works every time in every situation, and that some of the strategies or options we discuss come with risks or may not be safe or realistic options for everyone. In particular, people who are already at risk for state control and surveillance, such as low-income people, people of color, transgender and gender non-conforming people, younger parents, older parents, immigrants, people who use drugs, and people with disabilities, may face harsher consequences for any resistance to authorities or may be targeted as a result of being identified as belonging to one or more of these groups. Each individual should weigh their options based on their individual circumstances.

We also understand that this resource is not a solution to the systemic problem of human rights violations during childbirth. We acknowledge the deep and continued need to advocate for systemic change and the dismantling of systems that normalize the mistreatment and sanction the violence that so many pregnant people experience when seeking care. We salute the many dedicated organizations and advocates who continue to fight for structural change. While advocacy carried out within the context of individual care is of great importance, it is critical to strive for larger structural change that targets the current healthcare system and broader systems of oppression, including racism, sexism, transphobia, and classism, all of which deeply inform and enable mistreatment during childbirth.

Doulas provide critical care and support to pregnant people across all outcomes and experiences. Pregnancy Justice and Birth Justice Bar celebrate doulas' ongoing work across the spectrum of pregnancy. While doula communities discuss whether doulas can or should also be advocates, we absolutely believe doulas should feel empowered to act as critical advocates for their clients in a way that centers the birthing person, their needs, and their rights. Because power dynamics between medical providers and doulas can interfere with this advocacy, we hope to provide a range of ideas for intervention and advocacy, in the hope that doulas and birthing people will together identify what approaches would feel most supportive and hold the greatest potential for success.

## A note on terms

Throughout this report, we use the term "pregnant people" as well as the term "pregnant women." This is because in the face of "fetal personhood," it is important to center pregnant women and all pregnant people as persons entitled to dignity and the right to make autonomous decisions about their bodies, health and lives. And while the majority of people who become pregnant are cisgender women, trans men and nonbinary people's experiences of pregnancy are shaped by gender identity realities outside that of most cisgender women. Sexism based on the gender binary and the patriarchal drive to impose traditional gender roles on women and to erase trans and nonbinary people's experiences must be acknowledged. Our language reflects the broad community of people with the capacity for pregnancy.

# How is this resource structured?

The resource is divided into six sections, with a focus on tools for everyday people to defend human rights during pregnancy and birth:

1	<b>INTRODUCTION</b> Key concepts, with an overview of rights violations during birth.
2	<b>BIRTH RIGHTS</b> Civil and human rights held by people giving birth, key legal and ethical principles that establish and affirm those rights, as well as the limitations of those rights in practice.
3	<b>DURING A VIOLATION</b> Ideas and resources that birthing people, doulas, and other folks offering support to a birthing person can use to advocate in the birthing room.
4	<b>AFTER A VIOLATION</b> Resources and options that might be available after harm occurs, including possible avenues for seeking redress or sharing your story.
5	<b>MOVING TOWARDS BIRTH JUSTICE</b> The Birth Justice framework; how to dismantle systems that normalize mistreatment and violence during pregnancy and birth.
6	<b>RESOURCES</b> Glossary, list of organizations, notes, and appendix.

# Should you find a lawyer?

While this resource is grounded in legal research and has been reviewed by many lawyers, most of the rights we talk about here won't be well understood by lawyers outside of this field, and most people who experience a violation won't find justice in the legal system.

That's part of why we made this resource. It takes everyday people like you to defend human rights.

Many people who have sought legal help for a violation during pregnancy or birth have been retraumatized, as they have found the process intimidating, degrading, and invalidating. This is not to dissuade you from pursuing justice, but to give you fair warning.

Birth Justice Bar exists to help lawyers take cases and to provide better representation when they do, but BJB does not take clients as an organization. We maintain a public list of members by state, looking for an attorney in your state from that list might be a good place to start, via our website at birthjusticebar.org. Pregnancy Justice provides criminal defense for individuals facing investigation, arrest, or detainment related to any pregnancy outcome or those forced to have a surgery because of pregnancy. Contact Pregnancy Justice at (212) 255-9252 or via our website at pregnancyjusticeus.org.

We hope the resources offered here help you navigate these difficult issues with more tools and confidence.

**Feedback** We welcome additional feedback about this resource, including about how it may or may not be helpful to you, your loved ones, or your clients. We envision this as a living document; it was first published in 2020, with this edition published in 2025. We hope to continue to update it as we continue to learn what is helpful and needed, as based on the feedback we receive from you. If you would like to get in touch with us to share your thoughts, please contact us at info@pregnancyjusticeus.org or info@birthjusticebar.org.

# **Mistreatment and Abuse**

The problem of mistreatment during childbirth is not new, but in recent history we did not have shared words, definitions, or categories for the problem. Words like mistreatment, abuse, disrespect, violence, obstetric violence, and obstetric racism have been used to describe this experience.

Researchers from all over the world have been working to define shared categories so that mistreatment can be accurately measured and then fixed. This work is ongoing: researchers are still finding new ways of describing and talking about this issue.

The following seven categories are used by researchers to label types of mistreatment. Researchers are also creating sets of examples that fall under each category. Having a common language can help lead to solving the problem.

## Sets of Examples from Researchers

## Physical abuse

- Being beaten, slapped, kicked or pinched during delivery
- Being physically restrained to the bed or gagged during delivery
- Aggressive physical contact
- Refusal to provide anesthesia for an episiotomy

### Sexual abuse

- Sexual abuse, rape
- Inappropriate sexual contact
- Being touched without consent during labor or delivery in a way that triggers feelings from previous sexual abuse or rape

## Verbal abuse

- Harsh or rude language
- Judgmental or accusatory comments
- Threats of withholding treatment or poor outcomes
- Blame for poor outcomes
- Being shouted at or scolded by health care providers
- Threats to force you to accept treatment you did not want

# Stigma and discrimination

- Discrimination based on race, religion, nationality, disability (including HIV status), age, ethnic group, gender, sexual orientation, socioeconomic status
- Feeling unable to discuss concerns because of discrimination
- Feeling unable to discuss concerns or ask questions because the provider used language you did not understand

# Failure to meet professional standards of care

- Administering drug tests without informed consent
- Threatening to report you to child welfare authorities if you do not agree to a medical procedure or test
- Private or personal information shared without your consent
- Being uncovered or having people in the delivery room without your consent
- Not being asked before procedures are done
- Not being given information about procedures or options
- Not being given enough time to consider options
- Lack of informed consent
- Breaches of confidentiality
- Painful vaginal exams
- Refusal to provide pain relief
- Performance of unconsented surgical operations
- Neglect, abandonment, or long delays
- Skilled attendant absent at time of delivery
- Being ignored, refused requests for help, failure to respond for requests in a reasonable time
- Being pushed to accept options the health care provider wants

## Poor rapport between pregnant people and providers

- Poor communication
- Held back from asking questions or discussing concerns due to fear of providers or of disagreement with them
- Dismissal of concerns
- Language and interpretation issues
- Poor staff attitudes
- Lack of supportive care from health workers
- Denial or lack of birth companions
- Being treated as passive participants during childbirth
- Denial of food, fluids, or mobility

- Lack of respect for preferred birth positions
- Denial of traditional practices
- Objectification
- Detainment in facilities

Health system conditions and constraints

- Physical condition of facilities
- Staffing constraints
- Staffing shortages
- Supply constraints
- Lack of privacy
- Lack of redress
- Bribery and extortion
- Unclear fee structures
- Unreasonable requests by health workers

We share these examples to validate the broad range of acts considered mistreatment or abuse during birth. What would you add or change in these lists? We would add "not being asked before procedures are done" in the "physical abuse" category, in addition to where the researchers put it. See more about this in the endnotes section at the end of this resource.<sup>12</sup>

# **Medical Racism and Obstetric Racism**

The history of medicine in the United States is a history of racial subjugation.<sup>13</sup> The field of gynecology itself was developed through experimentation on enslaved women.<sup>14</sup> Because of the prevailing belief that Black women could not feel pain, experiments were conducted without anesthesia.<sup>15</sup> Women of color have always been subjected to unique forms of reproductive abuse, including forced reproduction, forced sterilization, and forced contraception.<sup>16</sup> Further, Indigenous women and Latine women have faced large-scale government-sponsored forced sterilization efforts: the Indian Health Service was one of the biggest perpetrators of forced sterilization against Indigenous women<sup>17</sup> and throughout the 1950s nearly one third of all Puerto Rican women underwent sterilization, largely all coercive or nonconsensual.<sup>18</sup>

Medical racism continues to be embedded in modern day clinical practice, affecting the medical treatment of Black, Indigenous and other communities of color. Numerous studies have shown that relative to non-Hispanic white women, Black women receive lower quality of obstetrical care, undertreatment of their pain, delayed treatment, inaccurate diagnoses, and mistreatment by their health care providers.<sup>19</sup> Such factors contribute to the disparities in negative health care experiences and poor outcomes among pregnant individuals, which is why experts like Dr. Karen Scott call the current inequities a "manufactured maternal mortality crisis."<sup>20</sup>

Some gradual reforms have addressed certain aspects of obstetric racism. One recent change is the removal of race and ethnicity as part of the Vaginal Birth After Cesarean Success Calculator ("VBAC calculator"). Used by healthcare providers as a gatekeeping device for patients wishing to attempt a VBAC,<sup>21</sup> the Calculator predicted the probability for a successful VBAC assessing various factors of a pregnant individual's clinical history, including indication for prior cesarean surgery, age, Body Mass Index (BMI),<sup>22</sup> and until recently, race or ethnicity, categorized by only three options: White, Black, or Hispanic. The calculator resulted in lower probabilities for Black and Latine pregnant people than non-Hispanic white pregnant people, thus leading to increased cesarean surgeries among people of color.<sup>23</sup> In the last 20 years, the number of cesareans has increased drastically, while the number of vaginal births after a cesarean have decreased accordingly.<sup>24</sup>

As a result of the VBAC calculator's discriminatory use of race as a risk factor, a disproportionate number of Black and Latine pregnant people interested in a VBAC were pressured or even forced to undergo repeat surgical births due to a perceived low calculator score.

While the new version of the VBAC calculator does not include race or ethnicity as relevant factors,<sup>25</sup> 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. This is just one example of medical racism in the context of pregnancy and birth meant to underscore how discriminatory ideas are embedded in routine practice.

To name this, Dr. Dána-Ain Davis coined the term, *"obstetric racism."* Obstetric racism describes the specific contours of mistreatment and discrimination faced by Black birthing people in the United States.<sup>26</sup> There are six dimensions: diagnostic lapses, medical abuse, intentionally causing pain, coercion, neglect or dismissiveness, and ceremonies of degradation.

Diagnostic Lapses	Intentionally causing pain	Neglect
Medical Abuse	Coercion	<b>Ceremonies of Degradation</b>

- *Diagnostic Lapses*: When a clinician's uninterrogated belief that Blackness is pathological leads them to de-emphasize or exaggerate or ignore a patient's symptoms, resulting in an inappropriate or lapsed diagnosis.
- Neglect, dismissiveness, or disrespect: When medical professionals ignore or dismiss a person's expressed need for reproductive help or care and/or treats them with disdain.
- Intentionally causing pain: When medical professionals fail to appropriately manage pain, which may be rooted in racialized beliefs about pain immunity as well as the absence of empathy for Black people's physical suffering, leading to a lack of internal motivation to alleviate or reduce Black suffering.
- *Coercion*: When medical professionals perform procedures without consent and/or intimidate patients to make decisions.
- Ceremonies of Degradation: 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 person(s) who may be viewed as a threat. In response, medical staff may deploy security, police, social services, or psychiatry to ensure compliance or to remove the 'threatening' person.
- *Medical Abuse*: This can occur when medical professionals engage in experimentation and/or (repetitive) behavior that is motivated not by concern for the patient but serves to validate the clinician's selfworth and upholds their domination over the patient.<sup>27</sup>

Expansion

Below are some examples of these dimensions and their manifestations in the health care system:<sup>28</sup>

### Diagnostic Lapses

- Ignoring patient symptoms or under-emphasizing risk
- Overemphasizing risk of certain procedures
- Assuming the patient has pre-existing conditions (high blood pressure, diabetes)

### **Medical Abuse**

- Disregarding patient choices or birth plans
- Drug testing
- Medical experimentation
- Non-consensual sterilization

# Intentionally causing pain

- Refusal to provide pain medicine or epidural
- Conducting unnecessary procedures
- Lack of empathy for physical suffering

### Coercion

- Failure to obtain informed consent
- Failure to provide complete information regarding birthing options
- Pressuring and intimidating patients to make certain decisions
- Threatening to call law enforcement or child protective services if a patient declines to consent
- Physical restraint or violence
- Court ordered treatment (e.g., forced cesareans, forced blood transfusions despite patient religious beliefs)

### Neglect, Dismissiveness, Disrespect

- Ignoring patient questions or requests
- Assigning blame for negative birth outcomes
- Denying the right to a companion during birth
- Treating patients with disdain and anger

### Ceremonies of Degradation

- "Sizing up" patients to determine worthiness
- Embarrassing, degrading, and humiliating patients
- Using security, police, social services, child protective services, or psychiatrists to intimidate patients
- Making sexual or inappropriate remarks



# **Barriers to Rights-Affirming Care**



Everyone has human rights, whether those rights are protected by society, the government, or not enforced at all. Pregnant and laboring people may face multiple barriers to accessing their human rights or, alternately, may find their human rights are violated for reasons other than or in addition to the fact that they are pregnant or giving birth.

# Barriers Faced by Pregnant People

- Being undocumented
- Not speaking English
- Being young
- Being poor
- Having a disability
- Being in foster care

- Experiencing racism
- Being incarcerated
- Experiencing violence
- Having a mental illness or substance use disorder
- Being transgender

You may encounter more or fewer barriers to having your human rights protected or enforced during pregnancy or birth depending on how many of these other circumstances you are experiencing. Your options for advocating for yourself will also depend on these barriers. Although we hope this resource is helpful to many people, we know that you may need to make adjustments to fit your particular situation. I have the right to...

Say "no" and **BEHEARD** 

Have my basic needs met.

Labor in the way that WORKS FOR ME

Birth vaginally.

Leave the hospital or birth center.

# **NOT TO BE TOUCHED**

Know all my options.

Feed my baby human milk.

**CHANGE** doctors, midwives or nurses.

Ask people to leave.

Informed by practitioners Demetra Seriki, CPM and China Tolliver

# **Section 2: Birth Rights**

# Know Your Rights<sup>29</sup>

I have the right to decide how, where, and with whom I give birth.



The international human rights framework recognizes your right to determine the circumstances of how and where you give birth. This right is not necessarily enshrined in U.S. law, but some of its key principles are recognized in state and federal law. In addition, many advocates are pursuing official recognition for the entire framework.

# What does this look like?

It is completely up to you whether you give birth at home, in a birth center, in a hospital, or any other place you wish—and you should not feel pressured about any one of those choices. There are no state laws that explicitly require a certain place of birth, though there are laws restricting what some providers can do and how facilities operate.

You may choose who is in the room and what you do during labor—including, but not limited to, walking around, eating and drinking, and positioning yourself however you feel comfortable. A birth plan is a tool some people use to communicate their intentions, but a birth plan is not recognized under the law and may not automatically be included in your medical chart. You may find that family or health care providers have strong opinions that differ from your preferences; you may have to speak up loudly and assert this right in the face of conflict. You may find it necessary to have legal counsel to help you effectively assert this right or defend you from opposition or punishment.



But there's more...

Your provider of choice might not be available to you, sometimes because they are not on call when you go into labor, because they are not licensed in your jurisdiction, or because state law limits their scope of practice. Facilities possess the right to say who can be on their premises, which means that your doula or support person could be forced to leave.

Your birthing preferences may be harshly judged by family, friends, or providers, who may employ coercive tactics to make you change your mind. Providers may threaten to involve child welfare authorities or police, based on choices you make during labor and delivery. Often such threats are simply coercive tactics, but sometimes authorities do in fact become involved. This can lead to criminal charges or consequences from the family policing system, especially for people who are more likely to be targeted for state control, such as low-income women, women of color, or drug-using women.

The right to access appropriate care throughout the course of pregnancy is encompassed by these principles. When a termination of pregnancy occurs, including miscarriage, access to care may be constrained by a provider, facility or state's interpretation of the law to mean that an individual patient can be refused interventions that the patient wants or needs.

Since the Supreme Court's ruling in Dobbs, pregnant people and their loved ones should be prepared to face more obstacles to care as a result of this current environment. The law on this issue is ever changing and the ability of providers, facilities, or states to impose their own interpretations of treatment decisions is increasing. Nonetheless, defenders of human rights should continue to advocate for the centrality of the pregnant person's decisions.

# I have the right to informed consent.

What is informed consent? Your provider must explain to you the risks, benefits, and alternatives for any and all medical procedures. If you are not aware, do not understand, or do not agree, the provider may not perform a procedure on you. No one can legally do anything to your body, or your baby, without your consent when you are conscious and competent. If they do, they are violating their ethical duties and standard of care, and may be committing battery on you. Battery is a legal word for unconsented touching that an individual can sue over. Battery can also be a criminal charge, but only a prosecutor can initiate a criminal case.

# What does this look like?

The "consent" forms provided by most hospitals are not equal to "informed consent." Their purpose is merely to memorialize that the facility has followed their informed consent protocol. Informed consent should be a conversation with your provider that describes the risks and the benefits and alternatives of each course of action, including doing nothing. But, many facilities will interpret a signed form to mean you consent to anything and everything. You can try writing on the form or crossing things off to document your limitations. Your signature on a consent form does not truly prove that you "consented," if you later express a lack of consent. However, it can be used against you later if you need to prove that you refused. You can demand full, accurate information before a procedure is performed, but it can be a challenge to advocate for the information and consent you are due. We often hear from individuals who were given drugs, drug tested, or advised to have procedures without being given full information about risks, benefits, and alternatives. You may experience adverse effects, feel misled, or feel left out of the decisionmaking process.



### But there's more...

Sometimes providers will indicate that you do not have time to ask questions because there is a medical emergency. However, even in an emergency, competent\* patients have the right to information about all suggested procedures. We know that people of color, those on state assistance, those suspected of drug use, and those who do not speak fluent English tend to be at greater risk of having their rights to informed consent violated.

As mentioned above, you may encounter coercion or consequences when you insist that providers respect your right to informed consent, or when you try to refuse a suggested procedure. This is especially true for procedures recommended for your baby after birth, including drug testing, because providers are told they must contact child welfare authorities if they believe that your refusal of recommended procedures indicates abuse or neglect (even though providers often over-report to the detriment of the provider-patient relationship).

\*A competent patient is one who is conscious and capable of making decisions.

# I have the right to refuse surgery or medical procedures.

U.S. courts have repeatedly held that people should not be forced to undergo medical procedures, including for the sake of someone else. You may refuse any procedure before it begins, even if you previously requested it or gave consent.

# What does this look like?

You can always say "no" to any procedure, test, or drug, even if it is life-saving. You do not have to give a reason, and you do not have to sign a form to make it official. The vast majority of labor-related procedures are non-emergency, and often saying "no" can buy time to access better information to make a thoughtful decision, without feeling pressure from providers or family members. Because some conditions or circumstances in pregnancy and labor can be life-threatening to both the pregnant person and the fetus, health care providers might be reluctant to accept a refusal. Providers may fear being held liable or criminally charged if you or your baby die or are injured. You are not responsible for protecting them from those consequences; they are responsible for following the law, including your right to refuse.



## But there's more...

Your right to make decisions in labor and delivery might be limited by someone's incorrect interpretation of the law. You may encounter coercion or consequences when you refuse a suggested procedure.

Your decision-making authority over your pregnancy may be challenged by someone else who thinks they have the authority to make decisions for your fetus.

Hospital staff may think they can make better decisions for the fetus than you. This is not well-supported in the law, even after the Supreme Court's decision in Dobbs, but several legal concepts combine to lead people to believe they can or should interfere in your health care decision-making during pregnancy: that health care providers can be liable for birth injuries, that the state can make laws restricting access to abortion, and that the state can protect children from abuse and neglect which may include limiting parental health care decisions in limited instances. Still, none of these legal concepts support limiting the pregnant person's authority to make decisions about their own healthcare during birth. Cases that are specifically about limiting a pregnant person's health care decisionmaking or authority for their fetus' healthcare are rare, not well-grounded in the law, or not considered by higher legal authority.

# I have the right to receive treatment when in labor or experiencing a medical emergency.

U.S. federal law requires most hospitals to admit and treat people who arrive in active labor or are experiencing any kind of medical emergency.\* Under this protection, you cannot be turned away because they have never seen you before, because of a disagreement with the provider about your care, because you do not have health insurance, or because you cannot pay. The medical facility has the obligation to stabilize a patient, but not necessarily to offer comprehensive, ongoing care.

# What does this look like?

If you are fearful about laboring at a particular facility for any reason, you have the option to leave and go elsewhere at any time. Even if you have never been to the new facility (or if you simply return to the same one in active labor), they must admit you for treatment if it is determined that you are having a medical emergency or are in active labor.

Even if you are in a state that has an abortion ban or restrictions in effect, the majority of hospitals must still comply with the federal Emergency Medical Treatment and Labor Act ("EMTALA") to provide life-saving and stabilizing treatment.<sup>30</sup> In the U.S. Supreme Court case *Idaho and Moyle, et al. v. United States,* Idaho is asserting that EMTALA does not conflict with the state's complete abortion ban.<sup>31</sup>

In June 2024, the Supreme Court dismissed the case, declining to fully affirm pregnant people's right to health care, instead sending the case back to the lower courts for further litigation and allowing Idaho doctors to provide medically necessary abortions for now.

In March 2025, the Department of Justice under President Trump dismissed the lawsuit filed by the Biden Administration, challenging Idaho's abortion ban as a violation of the emergency care requirements of EMTALA. St. Luke's Health System, Idaho's largest hospital system, filed a separate suit against Idaho and quickly obtained a court order to continue the litigation.

The current anti-abortion presidential administration further jeopardizes EMTALA, as federal agencies, like the U.S. Department of Health and Human Services, are responsible for enforcing the law's protections.

Healthcare providers must provide treatment—including abortion care—to stabilize the emergency medical condition. If you believe that you were denied emergency care due to your pregnancy status, you are entitled to file a complaint and have it investigated by HHS.<sup>32</sup>



But there's more...

You may encounter resistance when you try to leave a facility, but it is nevertheless your right to do so. Even if you leave "against medical advice" (AMA), the law does not permit your insurance company to automatically refuse to pay for covered care you have already received.

If you leave a facility and go to a new facility, there may be limits on what care is available to you under these circumstances, but your right to informed consent still applies. Your right to receive treatment does not mean that you can receive care without financial obligation to the facility; just because you cannot be turned away does not mean you will receive care free of charge, nor does it mean you can expect to receive all kinds of care. Insurance company policies often impact patient care and they can be hard to hold accountable for human and civil rights violations. Under EMTALA, you are entitled to receive the care needed for you to become "stable," which in the case of labor generally means giving birth. You may not receive the kind of care you would prefer, and what you experience as an emergency may not be considered a medical emergency under the law.

\*EMTALA applies to hospitals that take Medicare payments and have dedicated emergency rooms, which is about 80% of hospitals. You can learn more about EMTALA on many websites.<sup>33</sup>

If you encounter or expect difficulty exercising any of these rights, consider contacting an attorney in your area, who can advise you based on your specific situation. It is best to find someone in your state.

If you have an attorney willing to help but is unfamiliar with the law surrounding rights in childbirth, please refer them to Birth Justice Bar or Pregnancy Justice for subject matter expertise.

# Section 2: Birth Rights Drug Testing<sup>34</sup>

Pregnant and postpartum people have the right to refuse any medical procedure including a drug screening or test, and they have the right to refuse a drug screening or test on behalf of their children. Often, pregnant and postpartum people and their newborn babies are drug tested in medical settings without their knowledge or explicit informed consent, likely because there are certain exceptions to the right of refusal related to child abuse and neglect laws which vary state by state. Because of this, even when there is an option to refuse a drug screen or test it may come with consequences, such as a call to child welfare authorities.

Positive toxicology results are too often reported to government officials or used to support criminal child abuse investigations and prosecutions, civil child welfare investigations, termination of parental rights, and other nonmedical interventions. As 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 body tissue. It does not indicate abuse or addiction; recency, frequency, or amount of use; or impairment."<sup>35</sup>

While such medical test results should never be used to prosecute people or accuse them of bad parenting, it is additionally concerning that the test results may not even be accurate or reliable. Yet clinical drug testing carried out without specific informed consent is used as an excuse to intrude into people's lives with grave consequences, including criminal proceedings and family separation. It is important to know the facts about clinical drug testing.

# **Know the Facts**

# Drug testing adds to discrimination and racial profiling.

Current drug testing policies and practices disproportionately burden women of color. Despite the fact that drug use by Black and white women occurs at approximately the same rate in the United States, numerous studies and investigative news reports find that Black mothers and infants born to Black mothers are more likely than those born to white mothers to have been screened or tested for criminalized drugs. As leading researchers in one study concluded, "providers seemed to have used race, in addition to recognized risk criteria, as a factor in deciding whether to screen an infant for maternal illicit drug use."<sup>36</sup>

# Clinical drug test results are not reliable.37

A clinical drug test is an initial lab test done in a health care setting, meant to evaluate a patient's health and to design an appropriate treatment plan.

- The most common clinical test is a urine test. A clinical drug test is qualitative, meaning it establishes that a chemical compound is present in the bodily fluid. If a clinical drug test is positive, it creates a *presumption* that a drug is present. It does not *prove* that the drug is present.
- To determine whether the positive clinical result is accurate, a forensic test must be carried out to confirm the result.

A forensic drug test is a more rigorous drug test, which is why it meets evidentiary and testing requirements and protocols. It is a quantitative test, meaning it indicates *how much* of the chemical compound is present. Such tests, however, are also more expensive, which explains why health care providers often start with a clinical drug test.

# Clinical drug test results often show false positives.<sup>38</sup>

A positive clinical test does not prove the patient was using a particular substance; many clinical test results are wrong and imprecise. A false positive may occur in two situations: when the chemical compound is not present at all (in other words the result is just wrong), or when the chemical compound is present but comes from a lawful source, like medication.

Sometimes the test result does not even distinguish between a
positive for criminalized opioids, such as heroin, and noncriminalized opioids such as prescribed pain killers and the
treatment medications methadone and buprenorphine. The test
results are therefore not reliable and should not be treated as
concrete proof that the individual used a particular substance,
without at least confirmatory testing.

Drug tests may be conducted improperly or produce inaccurate results.

- Medical testing performed without informed consent is improper and violates common law principles and medical ethics.
- Examples from across the United States 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.<sup>39</sup>
- In Houston, Texas, a leaky roof damaged specimens held in a police lab; a subsequent state audit revealed serious contamination and employees lacking key qualifications and training required to

conduct and interpret drug and DNA test results. The lab was shut down and several people convicted of crimes were exonerated.<sup>40</sup>

# "Secret" drug testing undermines the doctor-patient relationship.

The use of drug testing without informed consent (especially without the patient's knowledge) and the practice of reporting the results to government officials violate physicians' ethical responsibility and can deter people from obtaining prenatal and other health care during pregnancy. For those who are pregnant and have a substance use disorder, it can deter them from seeking treatment.

- For this reason, prominent medical and public health associations, including the American College of Obstetricians and Gynecologists, American College of Nurse Midwives, American Society of Addiction Medicine, and many others, oppose prosecution of pregnant people based on drug use.<sup>41</sup> Many of these organizations additionally oppose mandatory or non-consensual drug testing of pregnant people.<sup>42</sup>
- The U.S. Supreme Court has ruled that it is unconstitutional to use the results of drug testing obtained under the guise of medical care for law enforcement purposes, without informed specific consent to a search for evidence of a crime.<sup>43</sup>

# Drug Testing Often Leads to Permanent Family Separation

States commonly use positive drug test results during labor and delivery to justify terminating the pregnant person's parental rights, leading to permanently separating families. In fact, allegations of parental neglect based on substance use has become one of the most common circumstances associated with children taken from their families by the family policing system.<sup>44</sup> This might take the form of an investigation, a formal court case, a trial, termination of parental rights, and permanent

separation of families; it might alternatively take the form of a "child protective" worker threatening to bring a case and using that threat to pressure a parent into "voluntarily" giving up their baby to a family member's care, or a stranger's.<sup>45</sup> The discriminatory manner in which drug tests are administered means that the family policing system often incorrectly and disproportionately determines that parents of color are unfit parents.<sup>46</sup> These determinations, in turn, perpetuate systemic abuses and the intergenerational trauma of forced separation among poor communities and communities of color.<sup>47</sup> What's more, despite the medically-misinformed stigma surrounding prenatal drug exposure or parents who use controlled substances, there is no reason to believe that a parent who uses drugs is more likely to abuse or neglect their child than one who does not.<sup>48</sup> Additionally, the risks associated with prenatal exposure to criminalized drugs have been found to be comparable to or less than those associated with legal substances much more commonly used.<sup>49</sup>

# **Section 2: Birth Rights**

Key Legal and Ethical Principles<sup>50</sup>

I have the right to possession and control of my own body as a core principle of liberty.

"No 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 unquestionable authority of law."

Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891)

# My right to refuse medical procedures is well-established in the law.

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages."

Schloendorff v. Society of New York Hosp., 105 N.E. 92 (N.Y. 1914)

"For our law to compel the Defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual and would impose a rule which would know no limits and one could not imagine where the line would be drawn."

McFall v. Shimp, 10 Pa. D. & C.3d 90 (Pa. Com. Pl., July 26, 1978)

"A competent person has a liberty interest under the Due Process Clause in refusing unwanted medical treatment." *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990)

# I have a right to privacy at all stages of pregnancy, as do all patients.

"All patients including pregnant women have a reasonable expectation of privacy in their medical information. All people, including pregnant women are protected by the Fourth Amendment's prohibition on non-consensual and warrantless searches – even when done in the guise of medical testing."

Ferguson v. City of Charleston, 532 U.S. 67 (2001)

"In virtually all cases the question of what is to be done is to be decided by the patient – the pregnant woman – on behalf of herself and the fetus. Exceptions, if any, to that rule will be '…extremely rare and truly exceptional. Indeed, some may doubt that there could ever be a situation extraordinary or compelling enough to justify a massive intrusion into a person's body, such as a cesarean section, against that person's will.' The fact that a fetus is presumed to be viable or that the pregnant [patient] is believed to be terminally ill does not provide a basis for stripping a pregnant woman of her constitutional and human rights. Neither the viability of the fetus nor the condition of the pregnant person justifies the removal of a person's constitutional and human rights."

In re A.C., 573 A.2d 1235, 1237 (1990)

"A woman's competent choice to refuse medical treatment as invasive as a cesarean section during pregnancy must be honored, even in circumstances where the choice may be harmful to her fetus....[A] woman's right to refuse invasive medical treatment, derived from her rights to privacy, bodily integrity, and religious liberty, is not diminished during pregnancy. The woman retains the same right to refuse invasive treatment, even of lifesaving or other beneficial nature, that she can exercise when she is not pregnant. The potential impact upon the fetus is not legally relevant... to the contrary, the Stallman court explicitly rejected the view that the woman's rights can be subordinated to fetal rights."

In re Baby Boy Doe, 632 N.E.2d 326, 326 and 332 (III. App. Ct. 1994)

"[T]he State may not override a pregnant woman's competent treatment decision, including refusal of recommended invasive medical procedures, to potentially save the life of the viable fetus." And concluding that this prohibition on State power also applies to blood transfusions, "a blood transfusion is an invasive medical procedure that interrupts a competent adult's bodily integrity." Further, holding that it was wrong to appoint a lawyer for the fetus.

In re Fetus Brown, 689 N.E.2d 397, 405 (III. App. 1997).

# Ethical and regulatory standards require health care providers to honor my decision-making.

"Pregnancy is not an exception to the principle that a decisionally capable patient has the right to refuse treatment, even treatment needed to maintain life. Therefore, a decisionally capable pregnant woman's decision to refuse recommended medical or surgical interventions should be respected...Obstetrician-gynecologists are discouraged in the strongest possible terms from the use of duress, manipulation, coercion, physical force, or threats, including threats to involve the courts or child protective services, to motivate women toward a specific clinical decision...The College opposes the use of coerced medical interventions for pregnant women, including the use of the courts to mandate medical interventions for unwilling patients."

American College of Obstetricians and Gynecologists, Committee Opinion Number 664, June 2016 "...lack of informed consent constitutes a human rights violation that could be attributed to States and national health systems...When practiced without a woman's consent, caesarian sections may amount to gender-based violence against women and even torture."

United Nations Report, A Human Rights Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services With a Focus on Childbirth and Obstetric Violence, July 2019

"Judicial intervention is inappropriate when a woman has made an informed refusal of a medical treatment designed to benefit her fetus. If an exceptional circumstance could be found in which a medical treatment poses an insignificant or no health risk to the woman, entails a minimal invasion of her bodily integrity, and would clearly prevent substantial and irreversible harm to her fetus, it might be appropriate for a physician to seek judicial intervention. However, the fundamental principle against compelled medical procedures should control in all cases which do not present such exceptional circumstances. The physician's duty is to provide appropriate information, such that the pregnant woman may make an informed and thoughtful decision, not to dictate the woman's decision."

American Medical Association, Policy Statement - H-420.969, Legal Interventions During Pregnancy (2016) "A hospital must protect and promote each patient's rights...The patient's rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment...The patient has the right to be free from all forms of abuse or harassment...All patients have the right to be free from physical or mental abuse, and corporal punishment. All patients have the right to be free from restraint or seclusion, of any form, imposed as a means of coercion, discipline, convenience, or retaliation by staff."

42 CFR 482.13, Medicare and Medicaid Programs; Hospital Conditions of Participation: Patients' Rights; Final Rule (2012).

"Recognizing and respecting patient rights directly impact the provision of care. Care, treatment, or services should be provided in a way that respects and fosters the patient's dignity, autonomy, positive self-regard, civil rights, and involvement in his or her care."

Joint Commission Standards, Rights and Responsibilities of the Individual, Overview (2009).

"The way to effectuate the birth of healthy babies is not .... through after-the-fact civil liability in tort for individual mothers, but rather through before-the-fact education of all women and families about prenatal development."

Stallman v. Youngquist, 531 N.E.2d 355, 361 (III. 1988).

# SECTION 3 DURING A VIOLATION

"We paid with renewable grief and one hundred thousand different fears. We paid with all our credit. All our credibility. **Because** we cared too much."

Alexis Pauline Gumbs, excerpted from "Birth Chorus," in Dub: Finding Ceremony Whether you are the support person or the person directly experiencing a violation, it can be scary, disorienting, and traumatic. Not all violations can be predicted or prevented, but if you are not aware that they may occur and do not anticipate them, its impact could be even greater. It is best to consider possible violations early, in order to come up with a plan for what you can do in the moment.

No definitive strategy works every time in every situation; indeed, some strategies come with risks. Particular populations, such as low-income women, immigrants, single women, youth, people of color, transgender and gender non-conforming people, people in foster care, people with a disability, and people who use drugs may face harsher consequences for their resistance to authorities or may be targeted as a result of being identified as belonging to one of those groups. Each individual should weigh their options based on their individual circumstances.

- Delay and try to buy time
- Document what is happening
- Restate your needs and wishes aloud
- Make eye contact or hold someone's hand
- Get more information
- Focus on what you have the power to do

# Delay and try to buy time

This can be done by repeatedly asserting that more time is needed, by asking the staff to answer questions, by asking the staff to involve more/other staff, by leaving, by calling in advocates to either physically be present, waiting in the hall, or making calls on their own. Consider asking for a consultation with a Patient Advocate, Ethics Committee member, Ombudsman or Translator. Even though these people generally work for the facility, their involvement can help you buy time. Offer to have your provider sign a form indicating that you won't hold them liable for your informed decision (see Acknowledgement of Informed Consent form, page 88 appendix). You will know your local circumstances and the pros and cons of different options.

Some of these ideas can increase the hostility of the providers threatening

harm in the first place. But sometimes, with enough delay, something will change (such as the baby being born) that sidesteps the violation.

#### **Document what is happening**

Take pictures of whatever you can: forms, signs, badges. Ask those with you to help. Some states and facilities have laws or rules against recording someone without their consent. Consider the pros and cons for your situation. It can be good to have a video or audio recording of a conversation/interaction – if not to use as evidence, then to use for validation. A recording can expose a broader problem or generate a community response.<sup>51</sup>

Take notes while things are happening. Having a record that you made in real time can help you process what happened. In addition, a record can help you prove what happened and take action. You can make handwritten notes or audio recorded notes. You can also ask your healthcare provider, "Is this being recorded in my chart?" or "Can you make sure this is documented in my chart?" (See Documentation form, page 8 appendix.)

#### Restate your needs and wishes aloud

Having someone restate what you are saying, even just to you, can help. "I hear you saying," and then to other people in the room "I hear [person's name] saying 'stop' and 'no,' do you?" Restating your needs or saying it in another way might help or at least buy time. You can also say, "Does anyone else hear me saying this? I am saying Stop. I am saying No." If there is a language barrier, insist on an interpreter, which is your right.

#### Make eye contact or hold someone's hand

Whether you are experiencing the violation directly or supporting someone else through it, feeling connection can reduce trauma. Make eye contact. Make physical contact (hold a hand, or foot, or shoulder, whatever is comforting and consensual).

Hearing words of acknowledgement can reduce trauma: "I am here with you." "You're not alone." "I see what is happening." "I am bearing witness." "We will get through this together." Consider choosing a word that is meaningful or reassuring to say or hear in advance.

## **Get more information**

Ask to see whatever is relevant (the fetal heart rate tracings, the test results, or the ultrasound, for example). Ask to have policies explained or explained again or by someone else. Ask to see policies in writing. Ask to have information translated or interpreted. Ask for a second opinion.

#### Focus on what you have the power to do

Having a sense of control even in the face of trauma can improve recovery. Identify what choices remain, even if they are ridiculous or bad options. Acknowledge what is happening, that you are capable of surviving it because you are strong and resourceful.



# **Template Instructions**

How to use "Acknowledgement of Informed Consent" (See appendix page 87) This form can be used to buy time if you are trying to refuse a procedure when a provider is pressuring or threatening you. You may consider asking them to sign this document, thus relieving them from responsibility for your informed decision.

How to use "Documentation" (See appendix page 88)

Add a title, such as "My Labor Notes" or "Client X 2025"

Keeping track of the date and time helps add credibility and clarity to your notes.

Include details like names and numbers of people, and things they say, or what they do are useful. Shorthand is fine. The more consistent you are about keeping notes, the more credible your notes will be. For example, it can be helpful if you can say afterwards that you always write down every conversation with the provider. Find what works for you.

Example: In room w/ Ms. and Mr. X. Nurse on duty came in and said "Called doctor. Will be here to see you ASAP. Don't eat before she can talk to you."

# **Section 3: During a Violation**

# Pregnant People Who Are Using Drugs or Alcohol Have Rights<sup>52</sup>

Advocate for pregnant people who are using drugs or alcohol. People who use drugs or alcohol or have a history of substance abuse or a substance use disorder need additional advocacy and support because they may face additional barriers to respectful health care and freedom from violations during pregnancy and labor. If you see someone being refused pain relief during labor, being ordered to stop medication-assisted treatment during pregnancy or lactation, being drug tested without consent, or having confidential medical information shared – intervene. Share this information.

If you are being mistreated due to substance use or perceived substance use remember, *you have the right to...* 

<b>Receive medications</b> that are helping, including medication-assisted treatment for substance use	Be administered <mark>pain relief</mark> during labor
Prevent law enforcement or child protective services from accessing your medical records and exams without your consent	Maintain confidentiality in your medical records, including any history of substance use treatment
Receive information about the <b>risks,</b> <b>benefits and alternatives</b> of various procedures or treatments, including drug tests	<b>Refuse treatments</b> , tests, or medical procedures
Be treated with <b>respect and dignity</b>	Remain silent and <b>not speak</b> to the police
	·

Do not speak to the police without your lawyer present.

If you are facing criminal charges, contact Pregnancy Justice right away.

# SECTION 4 AFTER A VIOLATION

"What they took? What they took. Was touch. What they took. Was taste. Every touch become iron. Every taste become deficiency. Every day become craving. What they took."

# **Section 4: After a Violation**

How To Say: "What Happened To Me Was Not Okay"

## "What happened to me was not okay"53

If you or someone you know has experienced a violation during pregnancy or labor, you may want to communicate that what happened was not okay, or to prevent a similar violation from happening to anyone else. Nothing requires you or your support person to make a report or complaint about a violation. It is completely up to you. The possibilities for action range from small and fairly easy to much more complex and taxing.

In this section we lay out some options, described in clear steps, and explain the costs and potential benefits. Some people will find it works best to choose a combination of these options, to repeat or use variations, or to escalate from one to another.

Talk about what happened	File a formal complaint	Contact the media
Write your narrative	Work the system, be creative	Take direct action
Give direct feedback	Contact a state rep or another elected official	File a lawsuit

Talk about what happened	
ACTION STEPS: Find a trusted person who will sit down with you for a conversation about what happened. Focus on being able to talk openly and freely. This is an important part of the process. Even just saying, "this was not okay" out loud can be helpful.	
Costs: It can be traumatic to remember and talk about what happened. The process can stir up strong emotions that extend beyond the time of talking.	Benefits: It can be cathartic. Talking about it can help you release your story so you feel freer to attend to other life tasks. It can help you understand and accept what happened, and help you decide what kind of action you might want or need to

take.

#### Write your narrative

#### **ACTION STEPS:**

This document is just for you and your reference.

Record all you remember freeform, without worrying about grammar or phrasing. If you are uncertain about what happened or need clarification, ask others whom you trust and who were there to help you remember details. Go back and edit for clarity and to make sure it captures everything you remember.

# Costs:

It can be traumatic to remember and write down what happened. The process can stir up strong emotions that extend beyond the time of writing.

#### Benefits:

- It can be cathartic. Writing everything down can help you release your story so you feel freer to attend to other life tasks. It can help you understand and accept what happened, and help you decide what kind of action you might want or need to take.
- It can be helpful to have a record of the violation from your point of view, written as close to the time of violation as possible. This record can help you keep track of details that may be important later.
- The existence of a written record and the process of creating one can make it easier for you to talk about the violation with clarity and confidence.

# **Give direct feedback**

## **ACTION STEPS:**

Directly express to whoever was involved in the violation (a doctor, midwife, or nurse) that what happened was not okay. This can take the form of a written letter mailed to the person(s) responsible or an email to the person(s) responsible. The person who experienced the violation is best positioned to give this feedback but may also consent to have others who were present comment as well.

Refer to your narrative. Start a new document, intended to be shared, that is factual in tone. This new document will likely be much shorter and less detailed than your narrative.

#### We recommend including three main paragraphs:

- 1. Briefly describe the details of who you are, what happened, on what date and time.
- 2. Provide three to five of the most important supporting details about what happened and why it was a violation.
- 3. Describe why you are writing (to get them to apologize, to stop them from a certain practice, to change policy, etc). Make a clear ask.

Have someone else review the letter and incorporate their suggestions. Make edits. In your final version, include a formal address block and salutation, type it, and print it. Send it by both postal mail with delivery confirmation, and by email.

To ensure that the feedback is received or to increase the impact of your feedback, you may wish to consider sending copies to other people.

Brainstorm a list of people who may be relevant – perhaps the provider's boss or someone the provider collaborates with. Google "formal letter template" to make writing easier.

Costs:	Benefits:
<ul> <li>Whenever you communicate with</li></ul>	<ul> <li>The person might reflect on your</li></ul>
someone regarding a vulnerable	feedback and learn from it.

issue, it can feel stressful and • The person might become hard. You may never receive a aware of something they not response, which can add to the previously considered or been emotional difficulty. informed of. • Once delivered, the letter • The person might choose to may be shared. It might even make a change in how they be placed in your medical practice that improves the record. care they provide. • You might be labeled a "difficult patient." • It will take time to write and edit.

• The cost of postage.

50

# File a formal complaint.

## **ACTION STEPS:**

Submit feedback to an official entity that is there to collect such information. It is always best to strive for a professional and factual tone. Refer to the process for direct feedback above to help craft your statement.

Your first decision is to determine where you want to make a formal complaint. Every state has an agency or agencies that regulate health care providers. You can find your state's office online. Here are some common places to file formal complaints:

- All licensed providers, like doctors, are overseen by a state agency that has the power to receive formal complaints. There won't be an agency to complain to for an unlicensed provider. *Recommended Google search words: doctor complaint [Name of State] and sites ending in .gov.*
- Hospitals and health systems (like Kaiser) often have an internal complaints office. Recommended Google search words: [Name of Hospital or System] Patient Complaint or Patient Advocate or Omsbudsperson.
- Hospitals (and sometimes birth centers) are licensed by a state agency that has the power to receive formal complaints. *Recommended Google search words: hospital complaint [Name of State] and look for sites ending in .gov.*
- Accredited facilities have an accrediting organization that can receive formal complaints, such as the Joint Commission for hospitals, or the Commission for the Accreditation of Birth Centers.
- Accredited credentials like "MD" or "CNM" or "CPM" receive complaints for people with that credential. *Recommended Google search words:* accredit [Credential Type].
- Other agencies receive complaints about consumer protection or civil rights/human rights violations based on discrimination. Recommended Google search terms: consumer complaint [Name of State] or discrimination complaint [Name of State], and look for sites ending in .gov.

#### Costs:

- Your time and the cost of any computer/internet access or postage.
- The feeling of discouragement that may result from receiving no response or seeing no action taken.
- Depending on where you make the complaint, it might be made part of an official and/or public record.
- Official records can become evidence in subsequent legal cases; whatever you say in the complaint might be used to attack your credibility in a future legal proceeding.

#### Benefits:

- The responsible party might face an investigation, professional discipline, a fine, or other financial burden.
- The agency collecting complaints may see a trend. If others have also made complaints, this might make an investigation or discipline more likely now or in the future.
- The entity receiving the complaint might decide to change its requirements or policies to better prevent the harm you experienced.

# **Civil and Human Rights Complaints**

The Department of Health and Human Services (HHS) Office for Civil Rights (OCR) is responsible for enforcing our nation's civil rights laws. Section 42 USC 18116 (Section 1557) and its implementing regulation provide that an individual shall not be subjected to discrimination on the basis of race, color, national origin, sex, age, or disability while participating in any health program or activity that is receiving federal funds.

All pregnant and birthing people have a right to receive health care without mistreatment and discrimination. While people may not immediately recognize their experiences as a form of discrimination, we have come to understand that much of the mistreatment that happens during the perinatal period has its roots in some form of discrimination. If you believe you experienced discrimination on the basis of your pregnancy (or any of the protected categories), you may be interested in filing a complaint with OCR, who will investigate complaints and enforce protections if a violation is found.

There are several ways to file a complaint including through OCR's online portal or by mail, fax, or e-mail. OCR provides free language assistance services and services are accessible to persons with disabilities for those who may need those services. The complaint requires a detailed description of the alleged abuse, the name of the provider(s) who were part of the discriminatory event(s), and must be filed within 180 days of the event. If you fail to file within the allotted 180 days, there is still a possibility to file if you can demonstrate a "good cause" for the delay. More information on the OCR process and support can be found on the Elephant Circle website.<sup>54</sup>

# Mode of Responses:

- File a formal complaint with the Department of Health and Human Services Office for Civil Rights ("OCR").
- This involves submitting an account of any race, color, national origin, sex, age, or disability discrimination you may have experienced during the perinatal period.
- OCR will collect the information and has the power to investigate and issue recommendations. They can also enforce these recommendations by withholding federal funding from health facilities that do not comply.

• As with direct feedback, you can further escalate a formal complaint by copying it and sharing it more broadly, including with the media.

# **ACTION STEPS:**

- 1. Gather Information: Discrimination during the perinatal period can manifest in many different ways and can be difficult to articulate. See the above section on Barriers to Rights affirming care for more information and resources.
- 2. Consider Submitting an OCR Complaint The complaints are short written accounts that explain what happened and why you believe the treatment was discriminatory.

Any acts of discrimination that are prohibited under Section 1557 may be investigated and addressed by OCR if the facility gets federal funding. Find out if your health facility gets federal funding on the Tracking Accountability in Government Grants (TAGGS) website, under the "recipient search" tab.

There are exceptions for people who have "good cause" for needing more time than 180 days, it is worth stating that being postpartum is "good cause."

Anyone can draft the complaint. If you would like assistance with drafting an OCR complaint, please contact Elephant Circle.

3. Write the OCR Complaint

Name the health care or social service provider that discriminated against you.

Describe what happened. Explain why you believe what happened was discrimination (were you treated differently than other people on the basis of race, color, national origin, sex, age and/or disability? Does the facility or institution have a practice or policy that applies to everyone, but that has a discriminatory impact on a protected group?).

**4.** Submit the Complaint: Complaints can be submitted online on the HHS Office of Civil Rights Portal.

## 5. Prioritize Aftercare

Filing a complaint might be part of your healing journey, but it may also bring up hard feelings.

Make a plan to take care of yourself throughout the process. Consider reading the section on mental health support after experiencing violence or mistreatment in the Birth Rights resource.

<ul> <li>Costs:</li> <li>Cost of any computer/ internet access or postage that is necessary.</li> <li>The feeling of discouragement that may result from taking time and then hearing nothing or seeing no action taken.</li> </ul>	<ul> <li>Benefits:</li> <li>OCR will collect the information and may conduct an investigation. They have the power to issue recommendations to health facilities to ensure that violations do not continue to occur.</li> <li>OCR also has the power to enforce these recommendations by withholding federal funding from institutions that do not comply.</li> </ul>
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\*File a Civil Rights or Human Rights Complaint at State or Local Anti-Discrimination Agency

In addition to OCR complaints, several states and cities have human rights agencies (sometimes called Commissions) that recognize pregnancy discrimination as a violation of an individual's rights. A directory of state commissions of civil and human rights can be found on the US Commission on Civil Rights' website and you can contact Elephant Circle to strategize about your options.

Pregnancy Justice is working with local organizations in several states to file complaints on behalf of individuals who experienced discriminatory drug testing policies based on their pregnancy status. In these cases, pregnant individuals were drug-tested without their knowledge and informed consent, received a false positive, and were reported to the state family regulation agency for further investigation. While these complaints are still pending final decisions, the complaints have progressed in the legal process. Further, discriminatory drug testing can occur for reasons beyond pregnancy and gender, including race, national origin, and immigration status.

## Work the system, be creative.

# **ACTION STEPS:**

You may understand the system you're in well enough already to know of other ways to be heard or make change. If so, following the "Give direct feedback" recommendations, including communicating professionally and factually, may apply here too.

If not, start to learn more about who has power and how the system works. You can start by asking questions that will lead you to the right people: Who is in charge of making these decisions? Who do I need to talk to be heard? Who is good at listening to people? Who knows how to get things done?

You may also want to consider what resources you have, what you're good at, or already know how to do. Perhaps you will have professional experience that can inform you: we spoke to a mental health worker who knew that calling 911 from within a healthcare facility would get the medical director notified. When she tried this during labor, it helped her have a reasonable conversation with a person in power, with the result that she was supported in her medical decisionmaking from that point on. Of course, you should use extreme caution before calling the police.

People have used their theatrical skills to make creative costumes and scenes to draw attention to their issues, or have used their community connections to bring crowds of people to a public location to take collective action (see "Take Direct Action"). Social media and sharing information online also can be an effective tool to build momentum. You can use your creativity to come up with new solutions that no one has considered before.

Costs:	Benefits:
• The costs of new or creative ideas are, by definition, unknown. To minimize your risk, you may want to think through potential costs before taking action or get feedback from others.	<ul> <li>Trying something new could lead to a breakthrough.</li> <li>You could change the dynamic in your favor, even if only temporarily.</li> <li>You could get other people in positions of leadership</li> </ul>
Police involvement in	involved.

particular can add additional trauma, as well as additional bias or discrimination, especially based on race. Police have been known to detain or charge pregnant people for actions during pregnancy or labor that are otherwise legal.

 Public statements or documentation of your activity could be used as evidence in subsequent legal cases or used to attack your credibility. • You could show that you have tried many things, and could inspire others to join you or take interest.

#### Contact a state representative or other elected official.

#### **ACTION STEPS:**

The person who experienced the violation is best positioned to make this outreach, but may also consent to have others who were present share comments as well.

Because states are the primary regulators of health care providers and facilities, it is best to start with your state representatives rather than your members of Congress. Representatives often have multiple addresses.

Often it is best to email your local representative and then follow up with a phone call. You can expect to speak with a legislative staffer; it may help you to ask for someone who deals with health care-related matters.

It is best to be professional and factual when contacting a legislative office. Your letter to a representative may differ from direct feedback or a formal complaint in its organization and choice of details. Your communication is intended to alert the legislator to the kind of problem you experienced.

Add details that help the legislator to identify you, but restrict yourself to two pages.

In addition to a Google search for your state representative you can use Common Cause's "Find Your Representative" search function to locate an elected official in your state.

### Contact the Media.

# **ACTION STEPS:**

The person who experienced the violation is best positioned to contact the media but others who were present may do so as well.

Look for reporters in your area who report on health-related issues. Find people who regularly post about these issues on social media. Look for their email address, fill out a contact form, or send them a private message. Recommended Google search terms: [Name of your City] health reporter.

It is always best to be professional and factual. Refer to the process for direct feedback above to help craft your statement. Media will want to know who, what, where, when, and how, so be sure to include those details.

#### Costs:

- Media, especially social media, can bring out people and opposition you never even knew existed.
- You might encounter personal attacks, negative treatment, and criticism.
- It might be hard to get reporters to take an interest, or to dedicate time to your story, which can feel discouraging.
- It's easy to lose control of the narrative when the media pick up your story. Media outlets tend to emphasize the aspects of a story that the producers think fit their target audience, which may not be the same aspects you want highlighted. Your statements might be taken out of context. If the media publishes something, it

## Benefits:

- Media attention might help raise awareness and lead to more people coming forward to help and/or to add their voices.
- Media attention might help cause organizations to pay attention to an issue that they are otherwise reluctant to address.

can be accessible indefinitely and impossible to remove.	
<ul> <li>Once a story is online, your name may be associated with it for a very long time – this could have implications for future employers or others searching for you online for years to come and finding the story.</li> </ul>	

## Take direct action.

#### **ACTION STEPS:**

Involvement in creative community organizing can bring attention to your issue but also demonstrate the presence of systemic problems that go beyond your specific story.

Joining an existing group may be easier than creating one yourself. Community organizations, whether activist- or support-centered, are also important spaces to share with people who have experienced similar violations. Many established organizations link to other groups on their websites, which can be a way to find new allies.

Recommended Google search terms: birth justice [Name of your City], birth community organizing.

Costs:	Benefits:
<ul> <li>Because this is an indirect way to approach your specific harm, it takes time and progress may be slow.</li> </ul>	<ul> <li>Change that comes through community pressure is often more effective than litigation and can be tailored to the needs of the community.</li> <li>It can be healing and empowering to take action with other people and to support people who have had a similar experience.</li> </ul>

# File a Lawsuit.

#### **ACTION STEPS:**

The person who experienced the violation must initiate the lawsuit.

We provide information about finding an attorney in another section of this resource.

The vast majority of people who are harmed as a result of their health care do not sue, largely because a lawsuit requires time, resources, and emotional capacity.

After experiencing a trauma, some people find it hard to go through an entire legal ordeal. Some people may also be unaware that they might have a legal case.

In addition to their health care rights, their civil rights or consumer protection rights may have been violated.

Recommended Google search terms: [Name of your City/State], bar association, pro bono services.

Costs:	Benefits:
<ul> <li>Lawsuits cost a considerable amount of money, even if you are able to spread out and recoup the costs.</li> <li>Even with the services of an attorney, a lawsuit can take a lot of your time and last many years.</li> <li>Without an attorney, a lawsuit requires the amount of attention of at least a part-time job.</li> <li>Any lawsuit carries the risk not only of losing, but of creating bad precedent for future cases.</li> <li>If the individual loses the case,</li> </ul>	<ul> <li>The offending party is forced to respond in some way.</li> <li>Information may come to light that might not otherwise be revealed.</li> <li>Money damages might be recovered.</li> <li>The facility might make policy changes in response to the lawsuit.</li> <li>A lawsuit might lead to settlement negotiations.</li> </ul>

they may need to pay fees for the other side.

- A lawsuit puts the facility and provider in a defensive position and may render them less likely to talk or negotiate, at least in the near term.
- While a lawsuit cannot undo the harm suffered and never truly make you whole, it might still be empowering to assert your rights publicly and in court.

# **Section 4: After a Violation**

How to access your medical records Obtaining your medical records after a violation can be important for many reasons. If you are considering legal action, your medical records will be a key source of evidence and will reveal barriers and opportunities in your case. Your records can also help you reach a better understanding of what happened from the provider or facility point of view. Your records may also reveal inconsistencies between what you remember happening and what the hospital or doctor recorded. Reading your records, therefore, can also be retraumatizing and/or frustrating. Even the process of requesting and obtaining your records can be a challenge. But, again, requesting and getting hold of your records can be important and useful. This document is intended to help you understand the process for requesting your records and what to expect.

You have the right to see and receive

a copy of your medical records under the federal law known as "HIPAA" (the Health Insurance Portability and Accountability Act). HIPAA is such a big and complex law, that many facilities and providers have a specific staff person tasked with ensuring compliance with the law. States also have laws that give you rights to your medical records. These laws have to be as broad or broader than the federal law. Under the federal law you have to receive a copy of your records within 30 days of making the request. In some states it should take less than 30 days. Under HIPAA, the hospital can charge a fee for copying your records, but the fee must be reasonable. You also have a right to your records even if you owe money for health care services. If you find errors in your records, you have a right to request corrections and to have your corrections included as an attachment, even if the doctor does not agree.

#### Request your records.

There is no standard form or process. You may have to fill out a form used by the facility or provider that states you are giving them your permission to release your records. These forms generally let you say who the records are for (you, your attorney, or another provider). You may just be able to send an email or a letter, or make the request over the phone. Be prepared with information about yourself and the service you want records for when you make your request.

If you have not received your records within 30 days (or sooner in some states), call the provider or facility to follow up. If you cannot get through to the provider or facility, try to locate the HIPAA compliance officer or privacy officer for the facility and give them a call.<sup>55</sup>

#### Review your records

Your first look at your records can be confusing. Unless you are used to reading medical records, you may not know where to look or how to read them. *Here are some keys to decoding your records*:

- Start by looking for names and dates that coincide with names and dates you know or make sense to you, that can help you begin to understand how the chart is organized.
- Expect repetition (often charts include copies of other pages of the chart).
- Expect jargon, like abbreviations and special terms. Highlight those you don't understand. You can look up those abbreviations online. Once you decode one or two abbreviations or special words, a lot of other terms may make more sense.

Ultimately, you may need to have a medical expert look at your records to help you understand them. If you are considering a lawsuit, a medical expert will eventually have to review your records.

#### Make corrections

You have a right to request that corrections to your records be made. When

you review your records, consider taking notes on a separate piece of paper or in a separate computer document. Keep track of the page number, the error, and the correction. If you find errors you want corrected, contact the provider or facility and ask them what their process is. There is no standard process. Nevertheless, be prepared with a copy of the pages that need correcting, and a written document describing what needs to be corrected. If the provider or facility refuses to make the corrections, they should notify you of that in writing, and that notice should be included in your record. You can reply to that notice and request that your requested corrections be included as a page in your records. If you feel that the refusal to correct/denial of your request to correct your records is unjust or may harm you (if, for example, it contains information about your health that if relied on in the future could cause you harm), you can submit a complaint to the U.S. Department of Health and Human Services.

If you want to learn more, many resources (including videos) are available on this subject through the Department of Health and Human Services. Try searching "HHS HIPAA guidance."

# **Section 4: After a Violation**

How to find an affordable lawyer<sup>56</sup>

# Fees

Legal fees vary widely; don't be surprised if your attorney charges from \$150 to over \$500 per hour. Rates vary by specialty, experience, region, and business model. Lawyers also use different fee arrangements from hourly fees to a "contingency fee." Some lawyers may allow you to create a payment plan. To raise money for legal fees, some people have used crowdfunding websites.



If you cannot afford full representation, you may be able to receive "limited" or "unbundled" legal services. This provides you with a way to reduce cost by doing some work yourself, while getting the advice or consultation services of an attorney for some parts of your case.

# Right to an attorney

If you are accused of a crime, you have the right to be represented by a lawyer in any case in which you could be incarcerated for six months or more. State constitutions may guarantee that right for lesser crimes. Youth have a right to counsel in juvenile court proceedings. Forty states and D.C. provide a statutory right to counsel for parents with child protection cases. More generally, for non-criminal cases, there is no standard right to counsel.

#### Pro se resources

Many states provide resources for people who are representing themselves, the legal term for which is "pro se." Consider contacting the courts in your area to ask a clerk what support the court can provide for pro se litigants. Departments and agencies of both the state and federal governments often employ staff lawyers who can help the general public without charge in some situations. If your legal issue comes from an agency, consider contacting that agency directly with specific questions. Civil rights agencies, or Commissions, and the Office of Civil Rights at HHS, are set up so that you can file complaints simply and without an attorney.

## Referrals

Bar associations in most communities make referrals according to specific areas of law, helping you to find a lawyer with the right experience and practice concentration.

Birth Justice Bar has member attorneys who are willing to work on birth justice cases. When we do not have a member attorney in your jurisdiction, we encourage people to find an attorney willing to consult with BJB to ensure that the unique issues related to childbirth are considered.

# **Section 4: After a Violation**

How to approach a lawyer

This resource is for individuals seeking to bring a legal case to redress a violation of rights during birth. It is not itself to be considered legal advice.

Statutes of limitations restrict the amount of time that may pass after a violation before you bring a claim. As soon as you begin to consider filing a claim, check your state's statute of limitations for the type of claim you are seeking to bring.

Different types of claims - the kind of legal claim you are making - have different statutes of limitations in different states. For example, battery often has a 1-year limit, while medical malpractice has a 1- or 2-year limit. If you fail to file a case within the time limit set, the statute of limitations is said to have run, leaving you without a right to file the claim, no matter how strong your case or how grave your injuries.

For an example of a letter to a lawyer, see appendix page 89.

# **Section 4: After a Violation**

Mental Health Support after Experiencing Violence or Mistreatment

Individuals will respond differently after experiencing a traumatic event. There is no one right way to process trauma. Some people may need to talk about it right away. Other people may not want to talk about it at all or not until a long time after the experience. Even just witnessing a traumatic event can require time to heal and benefit from support in that process. Here are some ideas and resources that may help. It's also important to know that the impact of violence or mistreatment may be compounded by previous traumas.<sup>57</sup>

## Discharge

Upon discharge (when a patient is leaving the hospital), ask for written instructions for follow-up care that address traumatic birth and/or postpartum mental health. You may consider asking for a referral to a mental health provider or a social worker. Even though trust may be broken with people at the facility where the violation occurred, it can be empowering to ask for these resources and can force, or at least encourage, the provider to consider the impact of what happened. Advocate for continued access to medications that are or have been helpful. Note that when the child welfare or family policing system is involved even proactive steps like this can lead to unwarranted state intervention, so proceed carefully.

# Counseling

You may find counseling useful immediately after the event or at some much later time. Individual preferences and options for counseling vary widely. Finding a culturally-matched provider can be helpful, especially if racism or other bias played a role in the traumatic event. Medicaid participants should be able to access behavioral health services. Consider looking into whether there is a support group or free counseling clinic in your area. All-Options also has a free Talkline for talking through pregnancy-related issues.

# Books, articles and websites

We provide some recommendations in the "Notes" section of this resource. If you are looking for a book, consider search terms like "birth trauma," "trauma exposure," "postpartum mental health," or "infant mental health." Some resources may fail to acknowledge the intersecting issues people who are young, not English-speaking, living in poverty, undocumented, people of color, in foster care, incarcerated, transgender or gender non-confirming may face.

Numerous online resources on this topic exist; new ones are frequently being posted. Use your judgment, because the usefulness of these resources will vary from person to person. You might consider developing a list of resources specific to your area or specific to your network that you can share with others. Search terms like "perinatal loss," "postpartum mental health," and "trauma recovery" will help you find these resources.

Some enduring websites on pregnancy loss include:

- American Pregnancy Association
- BabyLoss
- MISS Foundation
- Share Pregnancy and Infant Loss Support

Some long-term mental health websites that include information for postpartum disorders, trauma or perinatal mental health include:

- Postpartum Support International
- National Institute of Mental Health, the Anxiety and Depression Association of America
- National Perinatal Association

# Resources for people who have substance use disorders

The postpartum period can be a particularly vulnerable time for people who have a history of substance abuse or a substance use disorder, especially if there is new trauma to deal with. Finding treatment providers who are knowledgeable about and sensitive to issues regarding drugs and drug use will likely be challenging. In addition, being honest about a problem with drugs may also put the person at risk of being reported to child welfare authorities. It may be best to try to find trustworthy and effective providers through word of mouth. When researching providers, ask if they have a "harm reduction" approach. Groups such as Vocal NY, Harm Reduction Coalition, the Center for Optimal Living (NY), the Center for Harm Reduction Therapy (CA), or any drug user "union" or needle exchange group might also be a good place to find support or referrals. The National Perinatal Association and the Academy of Perinatal Harm Reduction also have some great resources on substance use related to pregnancy.

Additionally, a search for addiction medicine and ob-gyn will help people find practitioners that have specialties in both areas. There are bridge programs that assist in pre- and post-natal care as well as substance use.

The Substance Abuse and Mental Health Services Administration has a resource that is supposed to help people find treatment. However, the sad truth is that there is not enough high quality drug treatment for all the people in the United States who could benefit from it and who want it. Lack of access is especially bad for pregnant and parenting people.

## SECTION 5 MOVING TOVARDS BIRTHJUSTICE

"And trust also this. You the we. **The this beyond this.** The form and the function the content and the coeffcient. And any of that can change (You. Us.) And when it changes, *let it change everything.*"

Alexis Pauline Gumbs, excerpted from "Birth Chorus," in Dub: Finding Ceremony This resource focuses on identifying and responding to individual violations experienced during pregnancy, labor, or postpartum. Individual violations, however, happen in the context of larger systems that systematically fail pregnant people. Experience with individual violations may lead you to become interested in this broader system. Seeing a pattern or the same type of violation happening over and over again may lead you to become interested in this broader system. Here are some ideas and recommendations for moving from individual violations and towards work for birth justice.

Birth Justice is a subset of the reproductive justice framework. Reproductive Justice was developed by women of color in order to articulate the various ways reproduction is impacted by systems of power and oppression (such as racism) and the intersectional issues that need to be addressed in order to bring about a better, healthier, and more just way of dealing life. The authors of Radical Reproductive Justice (Loretta J. Ross, Lynn Roberts, Erika Derkas, Whitney Peoples, and Pamela Bridgewater) explain:



"We created a radical shift from 'choice' to 'justice' to locate women's autonomy and self-determination in international human rights standards and laws, rather than in the constitutionally limited concepts of individual rights and privacy. We challenged how liberal ideology misused the concepts of rights and justice to situate responsibility for health and wellness in individual choices, while ignoring the institutionalized barriers that constrict individual choices such as racism, homophobia, sexism, classism, ableism, or xenophobia, or more simply, lack of access to appropriate and comprehensive healthcare."

Despite this broad and brilliant vision of Reproductive Justice, early articulations of it included remarkably little about childbirth as one of the many outcomes of pregnancy that warrant advocacy and attention.

#### Birth Justice fills this gap.

Like Reproductive Justice, Birth Justice is about more than quality health care during birth and the rights of people giving birth. Like Reproductive Justice, Birth Justice includes abortion as one of many possible outcomes of pregnancy. Birth Justice recognizes that people should have respectful, appropriate health care and have their rights recognized, regardless of pregnancy outcome. To achieve this we must also strive to end various forms of oppression – including but not limited to racism and sexism – that prevent too many people from accessing the health care they need and from exercising the rights they should have.

Perinatal Healthcare	Perinatal Rights	Birth Justice
Approaches the problem as one of service delivery. Improving the service delivery system, by improving the kind of care people get during birth, and making sure everyone who needs care gets it, would lead to better birth outcomes.	Approaches the problem as one of rights. Pregnant people and those who provide care to them should have certain rights. Protecting rights would lead to perinatal health and the well-being of society.	Approaches the problem as one of structural inequality. Inequality stratifies people using laws and policies to advance the racial identity, gender position, and economic position of those in power. Inequality compromises perinatal health in many different ways. Challenging inequality is necessary for birth justice.

#### Moving Toward Birth Justice<sup>58</sup>



An analysis of power and oppression is critical to being able to move toward birth justice. There are many ways to learn more about institutionalized

barriers that constrict individual choices. One framework that is particularly useful is called the "Lens of Systemic Oppression" (also sometimes called the "4 I's of Oppression") which illustrates how oppression happens at the individual, interpersonal, institutional, and structural levels.

This framework will help you begin to take action in a strategic way. When you see individual, interpersonal, institutional and structural oppression playing out, you can begin to address each one in a unique way. It is possible that the violation you witnessed or experienced has roots in systemic oppression.

Another important step is to listen to and learn from those who have experienced racism, homophobia, transphobia, sexism, classism, ableism, or xenophobia in order to better understand how that has impacted the perinatal health care system and their experience in it.

This includes reading articles, essays, and books written by them, and supporting organizations already working toward Birth Justice. It is possible that by doing this, you will come to understand the violations you experienced or witnessed in a new way.

It is possible that when you see the same violations occurring over and over again, you will have new insight into the patterns. It is possible your priorities will shift or you will identify new or different conditions that need to be addressed.

Full actualization of Birth Justice entails moving the voices and organizations of people who have experienced offenses such as racism, transphobia, homophobia, sexism, classism, ableism, or xenophobia to the center of our minds, conversations, and priorities. In this way, we dismantle the hierarchies that create oppression in the first place, stop replicating these structures, and stop taking the forces that created the status quo for granted.



"Some days we held in the sky for you. Colored it with colors you would recognize...during those few seconds you imagined **you could live in there forever and be free.** Remember that."

Alexis Pauline Gumbs, excerpted from "Birth Chorus," in Dub: Finding Ceremony

#### Glossary

When speaking of drug use, we use person-first language throughout this resource (ex: "pregnant person who uses drugs"), in order to respect the humanity and autonomy of pregnant people who use drugs.

We use the term "family policing system" interchangeably with "child protective services," "CPS," or the "child welfare system," to denote the role of those systems in policing families.

#### A

"Against Medical Advice" or "AMA" – If a patient does not follow a recommended course of action, often the recommending provider may refer to the patient's action as "AMA," often entering a note to this effect in the patient's medical record. This action is taken to protect the provider and institution from potential malpractice liability arising from negative consequences that result from the patient's refusal. Note that such a refusal has no effect on reimbursement by the patient's health care insurance carrier.

#### B

Battery – in both criminal and malpractice law, an unconsented touching, particularly when the touch is offensive or harmful.

Bias – unfair judgment, whether conscious or subconscious, of a person or group as compared.

Birth center – a facility staffed by maternity care providers in which people receive care during pregnancy and birth. Independent birth centers are not formally affiliated with a hospital and are usually staffed by midwives, who often refer to birth centers for people who wish to give birth "in someone else's home."

#### С

Civil rights - a class of rights that protect individuals from overreach, primarily

by the government, but also in places of public accommodation.

Clinical drug testing – a drug test performed for health care purposes, as opposed to screening carried out by potential employers.

- False positive the results incorrectly indicate the presence of a chemical.
- Forensic test a drug test carried out in order to provide legal evidence.
- Positive toxicology test results indicating the presence of a chemical in the sample.
- Innocent positive test results indicating the presence of a chemical in the sample when the chemical is expected to be there (after eating a poppy seed bagel, for example).

CNM (Certified Nurse-Midwife), CPM (Certified Professional Midwife), or MD (Doctor of Medicine) - These initials placed after the name of a maternity care provider indicate the provider's credential. A credential, in turn, stands for the specific type and level of education the provider has received as well as the types of procedures, diagnosis, and treatment they can perform. Additional restrictions are imposed by a provider's license, if any. See license.

Coercion — also, coercive. Pressuring, pushing, or threatening someone to make a certain choice.

Community organizing – the act of coming together as a group and using methods to give people a voice to make a difference in the issues that affect them.

Competent – legally qualified or adequate. In the health care context, a competent patient is one who is conscious and capable of consenting to specific medical treatment.

Consent – also, informed consent. To consent is to give your approval. Informed consent means the patient has been given enough information about a proposed test or treatment and is able to give their approval or refusal to receive that test or treatment.

Criminalized drugs - also, illicit drugs. An illegal substance. Possession, or in pregnancy sometimes use, of drugs that can lead to arrest and/or criminal charges.

#### D

Delivery confirmation – a service available for a small charge at a post office

that will notify you when the letter or package you sent was delivered. This information can be useful when you mail important documents, like legal papers, that must be sent or received by a certain time.

#### E

Ethics Committee – also, Bioethics Committee, in a hospital, a formal group of medical, legal, and administrative personnel who give special attention to specific cases hard medical decisions, like when to remove life support. Patients can request a consult from the Ethics Committee when facing provider coercion or other behavior that they feel is unethical.

#### Н

Harm reduction – a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs.

Informed decision – a decision made with enough information. This is often the result of informed consent.

Institutionalized barriers – also, systemic problems or systems of power. These phrases refer to the way power works in society. Individuals who wield power are often given that power by their institutions, such as hospitals or police forces. When institutions always give some people power or always create problems for some people or groups of people, that means that it is the institutions themselves that make that division of power, even if it is enforced by individuals like nurses, clerks, or police officers.

Intersectional – overlapping and interdependent systems of discrimination based on multiple social categories, like race, class, and gender. For example, someone might face a very specific and individualized kind of discrimination because they are Black and female and gay. Dr. Kimberlé Crenshaw coined the term.

Intervention – also, medical procedure or medical treatment. Actions by doctors, midwives, or nurses that change the course of labor and birth. Interventions include administering medications or performing surgery.

#### J

Joint Commission – a private group that creates standards for hospitals to follow and certifies hospitals based on those standards. The Commission for the Accreditation of Birth Centers (CABC) creates standards for birth centers.

L

Laboring – also, active labor. Your body is actively working to help your baby be born by contracting (squeezing) the uterus. Sometimes doctors or midwives can determine that labor is "active" when the cervix, the entry to the uterus that leads to the vagina (birth canal), is dilated (open) at least 3 cm, as determined by a vaginal exam.

Legal counsel – another word for a lawyer or attorney who represents (works for) you. If your immediate reaction to hiring a lawyer is "I can't afford that," know that some cases are paid for by contingency fees: your lawyer does not charge you and gets paid only if they win your case. Their payment is a percentage of any money you are awarded by the losing side.

Liable – legally responsible for causing harm. If you caused the harm, you can be called the offending party. The harm may be called a violation. In medical malpractice cases, a provider can be held liable for substandard practice and subsequently be required to pay compensation to the person who suffered as a result of that substandard practice.

Liberty - freedom, being free.

License - permit that allows provider to practice legally, as spelled out in regulations. Licenses are granted by each state; as a result, requirements for licensing vary.

Litigation – the overall process of bringing a dispute to the court for judgment of whether a person caused harm. Redress is the solution or the acknowledgement of harm.

#### Μ

Malpractice – the failure of a health care provider to meet the standards for how they should practice.

#### 0

Official record – also documentation. A trustworthy account, usually written, of something that happened. Anyone can make a record of what happened by writing it down or recording it in some other way. Institutions like hospitals routinely document key facts about a patient and their treatment in an individual medical record. Because this information is recorded in a particular way and only by providers who have treated the patient, the medical record is considered official and can be used as evidence in a court of law.

Ombudsman – also, Ombud. Institutions often establish a position or an office to act as a neutral party in a dispute between a person and the institution. In hospitals, the ombudsman deals with complaints by patients against the hospital. A Patient Advocate may be hired to help the hospital, but not to help resolve patient complaints.

#### Ρ

Pro bono - free services provided by a lawyer or legal office.

Pro se litigants – people who represent themselves in court without an attorney.

#### R

Right to privacy – The U.S. Supreme Court has ruled that people have a right to be free from public scrutiny, and a right to be free to do personal things for themselves.

#### S

State representative - someone who was elected to serve in a state's legislative body, usually divided into House and Senate chambers. People who work for elected officials are often called Legislative Staffers or Aides. Legislative staffers typically meet with constituents (voters in the legislator's district), research and analyze issues for their boss, and sometimes serve as receptionists in legislative offices.

Statute of limitations – the amount of time you have to file a lawsuit. The amount of time varies depending on the type of lawsuit and the state in which the lawsuit is filed.

Substance use – using drugs or alcohol. Some definitions of substance use specify the use of drugs that are illegal, or street drugs. Substance Use Disorder, on the other hand, is a medical diagnosis that describes substance use that continues despite negative consequences.

Support person – someone who is with you to provide company, comfort, or other kind of help. This can be a family member, friend, or a professional.

Т

Traumatic – stressful in a way that can cause serious emotional and mental problems. Once you experience trauma, new events can remind you of that experience, causing you to be retraumatized – you might feel similar serious emotional or mental problems again.

Χ

Xenophobia – fear and hatred of people who are foreign or unfamiliar.

### Connections

#### About Us

Birth Justice Bar promotes human rights for childbearing people, including physical liberty, bodily integrity, autonomy, privacy, due process, equal protection, religious liberty, and informed consent. We build capacity for more representative lawyers and ways of lawyering, employ reproductive justice principles to shift the contours of legal advocacy and encourage innovate lawyering, seed movement lawyering in support of grassroots birth justice innovators, and work to humanize the legal profession by augmenting creativity, holistic, support, and authentic community engagement. Birth Justice Bar is a fiscally sponsored project of Elephant Circle.

Elephant Circle is on a mission to advance birth justice through Community Power, Public Health Law and Advocacy, and Movement Building. We are inspired by elephants who give birth within a circle of support, we envision a world where all people have a circle of support for the entire perinatal period.

Pregnancy Justice advances and defends the rights of pregnant people, no matter if they give birth, experience a pregnancy loss, or have an abortion. We advance our mission in four ways: by providing criminal defense, by advocating for legal and policy change, by publishing cutting-edge research, and by equipping partners in the field with analysis, training, and narrative framing.

You are welcome to reach out to us if you have questions or need help at info@pregnancyjusticeus.org , info@birthjusticebar.org, or admin@elephantcircle.org.

#### **Find More Doulas**

To find a doula, try searching "Your State + doula + association," or use the following resources

• Racial Doula's "Doula Training" Page

- Childbirth Connection's "working with a Labor Support Specialist/Doula"
- Doula Match
- National Black Doulas Association

#### **Birth Justice Work**



To find a list of organizations doing Birth Justice Work, consider looking at the list of past and present grantees of Groundswell's Birth Justice Fund or the Ms. Foundation' Birth Justice initiative.

#### **Harm Reduction**

For harm reduction help specific to the perinatal period start with the Academy of Perinatal Harm Reduction, including their guide with the National Harm Reduction Coalition, Pregnancy and Substance Use: A Harm Reduction Toolkit.

#### **Know that You Are Not Alone**

For more information about the separation of families nationally, consider the Movement for Family Power's Ground Zero Report, "Whatever they do, I'm her comfort, I'm her protector: How the foster system has become ground zero for the US drug war."

For more information about criminal cases brought against people because they are pregnant, consider Pregnancy Justice's report, The Rise of Pregnancy Criminalization, trends in pregnancy criminalization from 2006-2022.

#### Acknowledgments

We are grateful to the following people for working on this document, both the original 2020 version and this one: Vandana Apte, Heather Ault, Liani Caban, Colleen Campbell, Emma Evans, Deborah Fisch, Alexis Pauline Gumbs, Jacqueline Hammack, Kelly Keglovits, Samantha Lee, Indra Lusero, Anna Reed, Demetra Seriki, Dana Sussman, China Tolliver, Janessa Waiters, and Mahathi Vemireddy. We also are grateful to the following people who provided feedback for early drafts: Jamarah Amani, Kendall Bentsen, Alexis Commodore, Caitlin Dekker, NYC Doula Collective Advocacy Committee, Lynn Paltrow, Cristen Pascucci, Polly Pillen, Chanel Porchia–Albert, Jesse Remer, Mariel Rivera, Nancy Rosenbloom, Victoria St. Clair, Shawn Steiner, and Dawn Thompson.





#### Acknowledgement of Informed Consent

l,	, have been informed of what my			
provider,	, explained as serious risks to			
	consent to			
I have considered that information an	d I am nevertheless consciously and			
conscientiously declining the procedure and/or intervention at this time. I will let my				
provider know if I change my mind. I accept full responsibility for my decision based				
on the information presented to me. I appreciate that in honoring my decision my				
provider is acting legally and ethically and following the explicit guidelines of				
the American College of Obstetricians and Gynecologists with regard to the right of				
patients to refuse medical interventio	ns.			
Date:Time				
Signature:				
Signature of witness (optional):				
Name of witness (print):				

#### **Documentation of Informed Consent**

.

Date	Time	Who/What/When/Where	

#### Sample Letter to Lawyer

Confidential [Date]

Dear \_\_\_\_\_,

I am looking for a lawyer who is willing to take a novel case. I have been injured in a way that the current law does not commonly address. More and more people who have been harmed in this way are seeking redress and I am interested in considering legal action because of what happened to me.

Here are some examples of reporting on cases in this area:

- Ethics of the delivery room: Who's in control when you're giving birth?, The Independent (Dec. 18, 2017)
- Woman Sues Hospital Over Traumatic Birth That 'Turned Our Family Life Upside Down', Yahoo News (Nov. 19, 2015)
- Mother Accuses Doctors of Forcing a C-Section and Files Suit, The New York Times, (May 16, 2023)
- Cedars-Sinai faces federal civil rights investigation over treatment of Black mothers, The LA Times (July 11, 2023)

In my case, I was harmed at [Facility name] on [Date]. The providers involved in this incident were [Provider names]. The violation I experienced involved [Procedure name] and [How the procedure was performed or description of the nature of the violation]. The physical harms I suffer as a result of this experience are [Physical harms]. The physical harms my infant suffered as a result of this experience are [Physical harms]. The psychological harms I suffer as a result of this experience are [Psychological harms]. The financial harms I suffer as a result of this experience are [Financial costs]. I have my medical records from this event. Some examples of the legal claims that have been used in other cases like this include: battery, assault, medical malpractice, negligence, lack of informed consent, statutory patient's rights violations, breach of contract, fraud, violation of consumer protection laws, false advertising, violations of equal protection in public accommodations, and constitutional and human rights violations. We need lawyers who are willing to push the envelope and who are willing to consider making claims that are not common or that have not been made in quite the same way before. There is case law to support these ideas.

I know that there are advocacy organizations that will support this case if you are willing to represent me. Birth Justice Bar, birthrightsbar.org, is a membership association for lawyers working on these kinds of cases. They can help with finding experts, providing you with research, and helping you to learn more about this area and why cases like this need to be brought. Pregnancy Justice is also a resource and can provide model motions and write amicus briefs on behalf of experts in perinatal health care and the rights of pregnant people.

Thank you for your consideration,

[Name and contact information]



# BIRTH RIGHTS

A Resource for Everyday People to Defend Human Rights During Pregnancy and Birth







#### Endnotes

<sup>1</sup> At the beginning of each section, we include quotes from Dub: Finding Ceremony, by Alexis Pauline Gumbs, which explores themes of ancestry, Blackness, mothering, grief, harm, migration, and more. To begin, we chose "what you can see is actually enough," because what you see in terms of human rights violations is actually enough: you do not have to be an expert to know when something is wrong.

Dubravka Šimonović, Special Rapporteur on Violence Against Women, "A Human Rights-based Approach to Mistreatment and Violence Against Women in Reproductive Health Services with a Focus on Childbirth and Obstetric Violence," United Nations General Assembly Report (July 11, 2019), available at

https://digitallibrary.un.org/record/3823698?In=en#record-files-collapse-header.

<sup>2</sup> Yousra A. Mohamoud, et al., "Vital Signs: Maternity Care Experiences — United States, April 2023." MMWR Morb. Mortal Wkly. Rep. 2023, vol. 72, pp. 961–67, available at doi: http://dx.doi.org/10.15585/mmwr.mm7235e1; see also Saraswathi Vedam, et al., "The Giving Voice to Mothers Study: Inequity and Mistreatment during Pregnancy and Childbirth in the United States," Reproductive Health, vol 16, p. 77 (June 2019), available at doi:10.1186/s12978-019-0729-2

<sup>3</sup> Christine H. Morton, et al., "Bearing Witness: United States and Canadian Maternity Support Workers' Observations of Disrespectful Care in Childbirth," Birth, vol. 45, no. 3, pp. 263–74 (2018), available at <u>doi:10.1111/birt.12373.</u>

<sup>4</sup> Donna L. Hoyert, "Maternal mortality rates in the United States, 2021," National Center for Health Statistics (U.S.) (Mar. 16, 2023), available at https://stacks.cdc.gov/view/cdc/124678.

<sup>5</sup> Eugene Declercq & Laurie Zephyrin, "Maternal Mortality in the United States: A Primer," The Commonwealth Fund, Data Brief (Dec. 2020), available at <u>https://www.commonwealthfund.org/sites/default/files/2020-</u> <u>12/Declercq\_maternal\_mortality\_primer\_db.pdf</u>.

<sup>6</sup> National Partnership for Women & Families Issue Brief, "Maternity Care in the United States: We Can—and Must—Do Better," (Feb. 2020), available at https://nationalpartnership.org/wp-content/uploads/2023/02/maternity-care-in-the-united.pdf.

<sup>7</sup> 597 U.S. 215 (2022)

<sup>8</sup> See, e.g., Cassandra Jaramillo and Kavitha Surana, A Woman Died After Being Told It Would Be a "Crime" to Intervene in Her Miscarriage at a Texas Hospital, ProPublica, <u>https://www.propublica.org/article/josseli-barnica-</u> <u>death-miscarriage-texas-abortion-ban</u> (October 30, 2024).

<sup>9</sup> Kelly M. Treder, et al., "Abortion Bans Will Exacerbate Already Severe Racial Inequities in Maternal Mortality," Women's Health Issues, vol. 33, pp. 328-332 (June 8, 2023), available at <u>https://doi.org/10.1016/j.whi.2023.04.007</u>; Sara K. Redd, et al., "Racial/ethnic and educational inequities in restrictive abortion policy variation and adverse birth outcomes in the United States," BMC Health Services Research, vol. 21, pp. 1-15 (Oct. 22, 2021), available at https://doi.org/10.1186/s12913-021-07165-x.

<sup>10</sup> Eugene Declercq, et al., "The U.S. Maternal Health Divide: The Limited Maternal Health Services and Worse Outcomes of States Proposing New Abortion Restrictions," The Commonwealth Fund, Issue Brief (Dec. 14, 2022), available at <u>https://www.commonwealthfund.org/publications/issue-briefs/2022/dec/us-maternal-health-divide-limited-</u> <u>services-worse-outcomes</u>.

<sup>11</sup> Emily Badger, et al., "States with Abortion Bans are Among Least Supportive for Mothers and Children," N.Y. Times (Jul. 28, 2022), available at h<u>ttps://www.nytimes.com/2022/07/28/upshot/abortion-bans-states-social-services.html.</u>

<sup>12</sup> The words and categories come from research into mistreatment during labor and birth. We recommend "The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States," and "The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review." Based on our own experience, we would add some examples not yet included by the researchers:

- Being physically confined during labor or delivery.
- Being forced to undergo surgery, episiotomy, or other invasive medical procedure against your will.

We would also make sure that forced treatment is categorized as physical abuse and not only a failure to meet the professional standard of care. This is legally significant because there is a civil legal claim of battery for unconsented or offensive touch.

Other advocates have also attempted to visualize the range and relationship of violations during pregnancy and birth; for example, see Birth Monopoly's "rape culture pyramid."

<sup>13</sup> Timothy M. Smith, How the Legacy of Medical Racism Shapes U.S. Health Care Today, Am. Med. Ass'n (Jan. 31, 2022), https://www.ama-assn.org/delivering-care/health-equity/how-legacy-medical-racism-shapes-us-health-caretoday: Harry Kretchmer, A Brief History of Racism in Healthcare, World Econ. F. (July 23, 2020), https://www.weforum.org/agenda/2020/07/medical-racism-history-covid-19/.

<sup>14</sup> Sarah Zhang, The Surgeon Who Experimented on Slaves, Atlantic (Apr. 18, 2018), <u>https://www.theatlantic.com/health/archive/2018/04/j-marion-sims/558248/</u>

<sup>15</sup> Diedre Cooper Owens, Medical Bondage: Race, Gender and the Origins of American Gynecology, U. of Georgia Press (2017).

<sup>16</sup> Dána-Ain Davis, Obstetric Racism: The Racial Politics of Pregnancy, Labor and Birthing, Med. Anthropology, vol. 38, pp. 561 (2018).

<sup>17</sup> Loretta J. Ross & Rickie Solinger, <u>Reproductive Justice: An Introduction</u>, U. Cal. Press (2017), p. 50.

<sup>18</sup> Julissa Arce, The Long History of Forced Sterilization of Latinas, Unidos Blog (Dec. 16 2021) https://unidosus.org/blog/2021/12/16/the-long-history-of-forced-sterilization-oflatinas/#:~:text=In%20the%201930s%2C%20doctors%20in,women%20suffered%20the%20same%20fate.; Harriet B. Presser, The Role of Sterilization in Controlling Puerto Rican Fertility, Population Studies, vol. 23, no. 3, 1969, pp. 343-61. JSTOR, https://doi.org/10.2307/2172875.

<sup>19</sup> Brittany D. Chambers, et al., Clinicians' Perspectives on Racism and Black Women's Maternal Health, Womens Health Rep (New Rochelle), vol. 3, pp. 476-482 (May 4, 2022), available at doi: 10.1089/whr.2021.0148; Elizabeth Dayo, et al., Health in colour: black women, racism, and maternal health, Lancet Reg Health Am. (Jan. 2023), available at doi: 10.1016/j.lana.2022.100408.

<sup>20</sup> Dr. Karen A. Scott & Indra Lusero, The First Tool to Name Obstetric Racism Might Finally Push Policymakers Into Action, Ms. Magazine, (Oct. 4, 2023) https://msmagazine.com/2023/10/04/obstetric-racism-black-women-childbirth-maternal-health-discrimination/

<sup>21</sup> Indra Lusero, Anna Reed et al., Mobilizing the Office for Civil Rights' Authority to Address Obstetric Violence and Obstetric Racism, Elephant Circle (July 25, 2022),

https://static1.squarespace.com/static/57126eff60b5e92c3a226a53/t/62e87dd77018ef3c70b14acb/1659403736681/M obilizing+OCR+to+Address+Obstetric+Violence+and+Obstetric+Racism.pdf. <sup>22</sup> BMI is frequently used in reproductive health care decisions but is an imperfect and racially biased tool. Developed using data from white European men, it does not consider racial variations. In addition to its use in the VBAC Calculator, many fertility clinics maintain a BMI cut-off, after which they will not provide fertility treatment to prospective patients. Stigma and mistreatment towards fat people are common in all health care settings, but especially in reproductive health care. Fat people are consistently made to understand they are not "worthy" of having a child. Virginia Sole-Smith, "Hard to Conceive," New York Times Magazine (June 23, 2019).

<sup>23</sup> Indra Lusero, Anna Reed et al., Mobilizing the Office for Civil Rights' Authority to Address Obstetric Violence and Obstetric Racism, Elephant Circle (July 25, 2022),

https://static1.squarespace.com/static/57126eff60b5e92c3a226a53/t/62e87dd77018ef3c70b14acb/1659403736681/M obilizing+OCR+to+Address+Obstetric+Violence+and+Obstetric+Racism.pdf.

<sup>24</sup> Centers for Disease Control & Prevention,, Recent Trends in Vaginal Birth After Cesarean Delivery: United States, 2016-2018 (Mar. 2020), https://bit.ly/39rGCJW.

<sup>25</sup> William A. Grobman, et al., Prediction of vaginal birth after cesarean delivery in term gestations: a calculator without race or ethnicity, Obstetrics, vol. 225, pp. 664.E1.

<sup>26</sup> Dána-Ain Davis, Obstetric Racism: The Racial Politics of Pregnancy, Labor and Birthing, Med. Anthropology, vol. 38, pp. 561 (2018).

<sup>27</sup> Dána-Ain Davis, Cheyenne Varner & LeConté J. Dill, A Birth Story, Anthropology News (Aug. 27, 2021), <u>https://www.anthropology-news.org/articles/a-birth-story/</u>.

#### <sup>28</sup> Id.

<sup>29</sup> We do not provide a state-by-state analysis of the law, but these principles are common to every state. For a legal analysis of hospital visitation policies at birth we recommend this article: Ellen Trachman, COVID-19, Surrogacy, And Birthing Alone, Above the Law, April 1, 2020.

Several other organizations have also attempted to outline these rights, including:

- White Ribbon Alliance
- Birth Monopoly
- National Partnership for Women and Families, Childbirth Connection
- If/When/How: Lawyering for Reproductive Justice

<sup>30</sup> Emergency Medical Treatment and Labor Act, (EMTALA), 42 USC 1395dd (1986).

<sup>31</sup> U.S. Dept. HHS, HHS Secretary Xavier Becerra Statement on EMTALA Enforcement, May 1 2023 <u>https://www.hhs.gov/about/news/2023/05/01/hhs-secretary-xavier-becerra-statement-on-emtala-</u> <u>enforcement.html#:~:text=While%20many%20state%20laws%20have,stabilize%20the%20patient's%20emergency%20</u> <u>medical</u>.

<sup>32</sup> Centers for Medicare & Medicaid Services, Know Your Rights EMTALA, <u>https://www.cms.gov/files/document/emtala-know-your-rights.pdf</u>.

<sup>33</sup> See Centers for Medicare and Medicaid, Emergency Medical Treatment & Labor Act (EMTALA), (last updated Jan. 5, 2024); Centers for Medicare and Medicaid, Know Your Rights: Emergency Medical Treatment & Labor Act (EMTALA).

<sup>34</sup> Clinical Drug Testing of Pregnant People and Newborns, Pregnancy Justice, (last updated Jan. 2023) available on

Pregnancy Justice's Website.

Pregnancy Justice has also compiled statements from public health and medical groups against the punishment of pregnant people on its website.

<sup>35</sup> U.S. Dept. of Justice, Drugs, Crime, and the Justice System: A National Report from the Bureau of Justice Statistics 119 (1992), <u>https://bjs.ojp.gov/content/pub/pdf/dcjs-nrbjs.pdf</u>.

<sup>36</sup> Marc A. Ellsworth, et al., Infant Race Affects Application of Clinical Guidelines When Screening for Drugs of Abuse in Newborns, *Pediatrics*, vol. 125, pp. e1379–e1385 (June 2010), available at doi: 10.1542/peds.2008-3525; see also Jarlenski M et al., Association of Race With Urine Toxicology Testing Among Pregnant Patients During Labor and Delivery, JAMA Health Forum vol. 4 (2023) ("Black patients, regardless of history of substance use, had a greater probability of receiving a [Urine Toxicology Test] at delivery compared with White patients and other racial groups. However, Black patients did not have a higher probability of a positive test result than other racial groups.").

<sup>37</sup> Clinical Drug Testing of Pregnant People and Newborns, Pregnancy Justice, (last updated Jan. 2023) available on Pregnancy Justice's Website.

<sup>38</sup> Id.

<sup>39</sup> Report of the Motherisk Commission, Harmful Impacts: The Reliance on Hair Testing in Child Protection, (Feb. 2018) <u>https://files.ontario.ca/mag-motherisk-commission-report-en-2021-02-04.pdf</u>.

<sup>40</sup> Michael R. Bromwich Independent Investigator, Final Report of the Independent Investigator for the Houston Police Department Crime Laboratory and Property Room (June 2007) http://www.hpdlabinvestigation.org/reports/070613report.pdf.

<sup>41</sup> Medical and Public Health Group Statements Opposing Prosecution and Punishment of Pregnant People, Pregnancy Justice, available at https://www.pregnancyjusticeus.org/wp-content/uploads/2023/09/Medical-Public-Health-Statements-2023.pdf.

<sup>42</sup> Id.

<sup>43</sup> Ferguson v. Charleston, 532 U.S. 67 (2001).

<sup>44</sup> Parenting and Drug Use, Pregnancy Justice, available at <u>https://www.pregnancyjusticeus.org/wp-</u> <u>content/uploads/2022/12/parenting-and-drug-use-12-12.pdf</u>; How the Foster System has Become Ground Zero for the U.S. Drug War, Movement for Family Power, June 2020, available at <u>https://static1.squarespace.com/static/5be5ed0fd274cb7c8a5d0cba/t/5eefbd0056a96a1efe16d04a/1592769793700</u> /MFP\_DrugWar\_FosterSystem\_Summary\_FINALpdf.

<sup>45</sup> See Drug Tests Are Not Parenting Tests: The Fight to Reimagine Support for Pregnant People Who Use Drugs, Movement for Family Power, May 2023, available at https://www.movementforfamilypower.org/decrimhealth.

<sup>46</sup> *Id.*, pp. 16, 5.

<sup>47</sup> Id.

<sup>48</sup> Parenting and Drug Use, Pregnancy Justice, available at <u>https://www.pregnancyjusticeus.org/wp-content/uploads/2022/12/parenting-and-drug-use-12-12.pdf</u>.

<sup>49</sup> Id.

<sup>50</sup> The listed citations should be easy to search for with the information provided.

The U.N. Report on Obstetric Violence (Simonovic, Dubravka, A human rights-based approach to mistreatment and violence against women in reproductive health services with a focus on childbirth and obstetric violence: note / by the Secretary-General, 23 p. GENDER-BASED VIOLENCE WOMEN'S RIGHTS MATERNAL HEALTH SERVICES 2019 11 July 2019 Transmits report of the Special Rapporteur on Violence against Women, Dubravka Simonovic, pursuant to General Assembly resolution 71/170. UN) is available in multiple languages on the U.N.'s digital Library.

<sup>51</sup> For a start into specific recording laws by state, *see* Recording Calls and Conservations, Justia, (Feb. 2018) available at https://www.justia.com/documents/50-state-surveys-recording-calls-and-conversations.pdf.

<sup>52</sup> The Harm Reduction Coalition has created a "Pregnant People Who Use Drugs Toolkit."

The following organizations may also be helpful: Academy of Perinatal Harm Reduction, Vocal New York, The Center for Optimal Living, The Harm Reduction Therapy Center, National Perinatal Association also has resources on substance use related to pregnancy.

<sup>53</sup> Public Citizen has a great resource for making complaints related to health care, search "physician accountability" on their website.

Many people find sharing their violations with the public or the media to be helpful and sometimes more gratifying than making formal complaints:

- Birth Monopoly has a story-collection and obstetric violence mapping project

- Elephant Circle hosted two People' Tribunals to End Obstetric Violence and Obstetric Racism in 2023 and works with people who have experienced violations and want to make reports to OCR - Center for Reproductive Rights also collects information about rights violations

Other descriptions of the complaint-making process have been done by these organizations: Birthify, Citizens for Midwifery, on their resources for Midwives of Model Care, <u>International</u> Cesarean Awareness Network You can identify your elected representatives through any of the following ways:

- You can identify your elected representatives through any of the following way
- <u>Congress's</u> online State Representative Database
- <u>Open</u> States by Plural Policy
- <u>Common</u> Cause's "Find Your Representatives" resource

<sup>54</sup> Elephant Circle, https://www.elephantcircle.net/, (last visited Jan. 16, 2024).

<sup>55</sup> You can file a complaint of a HIPAA violation by visiting the Health and Human Services (HHS) website and searching for the "HIPAA complaint Process".

<sup>56</sup> State bar associations are a good place to start a search for an attorney. The American Bar Association also has recommendations on their "Find Legal Help" resource.

Civil Rights Counsel's 2016 Resource, "A National Survey On a Parent's Right to Counsel in State-Initiated Dependency and Termination of Parental Rights Cases" lists state-by-state information about right to counsel in dependency and termination of parental rights cases.

<sup>57</sup> Birthmark Doula Collective offers a Birth Trauma Toolkit (focused on New Orleans) available if you contact them at birthmarkdoulas@gmail.com

A specific strategy for dealing with trauma is available at the National Center on Domestic Violence, Trauma, and Mental Health (NCDVTMH)'s website.

Several organizations provide support for all kinds of situations:

- All Options
- The Trauma Stewardship
- March of Dimes specifically their resources on dealing with grief after the death of your baby

- Trauma Informed Oregon
- National Center DV Trauma
- The Center for Optimal Living
- National Perinatal Association specially their resources on Perinatal Substance Use

<sup>58</sup> The table in this section was inspired by the essay "Birth Justice Like Reproductive Justice: Reclaiming Our Time," in the publication Funding Equity: Birth Justice & Human Rights in Maternal & Infant Health, and "A New Vision for Advancing Our Movement for Reproductive Health, Reproductive Rights, and Reproductive Justice." Many online resources exist for learning about implicit bias, systemic oppression, racism:

- Harvard's "Project Implicit"
- National Equity Project's resource on "The Lens of Systemic Oppression"
- Rewire's 2018 article, "Race Isn't a Risk Factor in Maternal Health. Racism Is"
- The AMA Journal of Ethics's Article on Structural Racism -- Jonathan M. Metzl, MD, PhD and Dorothy E. Roberts, JD, Virtual Mentor, AMA Journal of Ethics, vol 16, Structural Competency Meets Structural Racism: Race, Politics, and the Structure of Medical Knowledge (Sept. 2014).

To learn more about Reproductive Justice, see:

- Black Mama Matter Alliance's 2018 resource on "Advancing Holistic Maternal Care for Black Women Through Policy."
- Forward Together's "Our Tools" resource tab.
- Sister Song "What is Reproductive Justice."

• National Latina Institute for Reproductive Justice

Finally, to learn more about Birth Justice, see:

- Forward Together's 2014 Article "We Need Doula Care to Achieve Reproductive Justice" written by Elizabeth Dawes Gay
- Elephant Circle
- Every Mother Count's Resource "Advancing Birth Justice: Community-Based Doula Models as a Standard of Care for Ending Racial Disparities"
- Southern Birth Justice Network
- Black Women's Birthing Justice's resource "What is Birth Justice"
- Ancient Song Doula Services