# BIRTH BISTAN

A resource for everyday people to defend human rights during labor and birth





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# Section 1 INTRODUCTION

66 What you can see is actually enough."

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

# ABOUT THIS RESOURCE

There is no point in pregnancy in which people lose their civil and human rights. And yet all over the world people often experience mistreatment and violations of their rights during pregnancy, whether they experience a pregnancy loss, seek to have an abortion or continue to birth. This reality is particularly present in the United States. In fact, a June 2019 study focusing on care during labor and delivery reported that one in six women "reported experiencing one or more types of mistreatment"; and that reported rates of mistreatment during childbirth were "consistently higher" for women of color.2 We also know that doulas and other people providing support to pregnant and birthing people often bear witness to rights violations of clients or loved ones. In a recent survey, 65% of doulas and nurses indicated that they had witnessed providers "occasionally" or "often" engage in procedures explicitly against their patients' wishes.3 Rights violations and mistreatment in childbirth take many different forms, including violations of the rights to privacy, bodily autonomy, and medical decisionmaking. These violations can take place during 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; and during incarceration when pregnant people are denied access to health care. And this all happens in the context of a U.S. health care system where extreme disparities persist for Indigenous and Black women in particular,4 where maternal mortality is rising, where some interventions are overused while other effective options are underused.6

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 don't have to be an expert to know when something is wrong.

<sup>1</sup> United Nations General Assembly Report. July 11, 2019. "A Human Rights-based Approach to Mistreatment and Violence Against Women in Reproductive Health Services With a Focus on Childbirth and Obstetric Violence." Available at, (<a href="https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/74/137">https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/74/137</a>).

<sup>2</sup> Vedam, Saraswathi, et al. "The Giving Voice to Mothers Study: Inequity and Mistreatment during Pregnancy and Childbirth in the United States." Reproductive Health, vol. 16, no. 1, June 2019, p. 77. BioMed Central, doi:10.1186/s12978-019-0729-2

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

<sup>4</sup> Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: <a href="http://dx.doi.org/10.15585/mmwr.mm6835a3external.icon">http://dx.doi.org/10.15585/mmwr.mm6835a3external.icon</a>.

<sup>5</sup> MacDorman, Marian F., et al. "Recent Increases in the U.S. Maternal Mortality Rate: Disentangling Trends From Measurement Issues." Obstetrics and Gynecology, vol. 128, no. 3, Sept. 2016, pp. 447–55. PubMed, doi:10.1097/AOG.000000000001556.

<sup>6</sup> National Partnership for Women & Families Issue Brief, Maternity Care in the United States: We Can - and Must - Do Better, February 2020. Available at (<a href="https://www.nationalpartnership.org/our-work/resources/health-care/maternity-care-in-the-united.pdf">https://www.nationalpartnership.org/our-work/resources/health-care/maternity-care-in-the-united.pdf</a>).

National Advocates for Pregnant Women (NAPW) and Birth Rights Bar Association (BRBA) 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 some concrete tools for pregnant people, doulas, partners, family members, and friends. This resource was inspired by our work with countless pregnant women, 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, and we have heard resounding feedback from people calling for more advocacy tools both to identify these rights and promote their observance, as well as more accessible information about avenues to address harm after it has occurred.

NAPW and BRBA are both non-profit advocacy organizations committed to the human rights of pregnant and birthing people, and many of the resources here are informed by legal, reproductive justice, and human rights frameworks. We also 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 recognize the deep and continued need to advocate for systemic change and to focus on dismantling systems that normalize the mistreatment and sanction the violence that so many pregnant people experience when seeking care. We recognize that change needs to happen structurally, and that there are many dedicated organizations and advocates that continue to fight for this structural change. In addition to the vital advocacy that can happen within the context of individual care, it is also critical to fight for larger structural change that targets the current health care system and broader systems of oppression, including racism, transphobia and classism that deeply inform and enable mistreatment during childbirth.

**Doulas provide critical care and** support to pregnant people across all outcomes and experiences, and NAPW and BRBA are grateful for the support doulas across the country provide to their clients across the spectrum of pregnancy every day. We also recognize that there is discussion within some doula communities regarding whether doulas can or should also be advocates. We absolutely believe doulas can be critical advocates, and should feel empowered to do so with their clients in a way that centers the birthing person, their needs, and their rights. We also recognize that dynamics between medical providers and doulas can be tricky. We hope to provide many different ideas for intervention and advocacy with the hope that doulas and birthing people can identify together what would feel most supportive and likely to work.

#### How is this resource structured? What does it include?

The resource is split in to six sections with a focus on tools for every day citizens to defend the human rights of people during labor and birth:

#### The first section, "Introduction"

 An introduction to key concepts and an overview of what rights violations during birth can look like.

#### The second section, "Birth Rights"

An overview of the civil and human rights people giving birth have, an overview of key legal and
ethical principles that establish and affirm those rights, as well as a discussion of the limitations
of those rights in practice.

#### The third section, "During a Violation"

• Offers some ideas and resources for what birthing people, doulas, and other folks offering support to a birthing person can do to advocate in the birthing room.

#### The fourth section, "After a Violation"

 Provides information about what resources and options might be available after harm occurs, including possible avenues for seeking redress or sharing your story.

#### The fifth section, "Moving Towards Birth Justice"

• Introduces the birth justice framework and talks about how to dismantle systems that normalize mistreatment and violence during pregnancy and birth.

#### The sixth section, "Resources"

Includes a glossary, list of organizations, and notes.

#### 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 defended by lawyers, and most who experience a violation won't find justice in the legal system.

That's part of why we made this resource, because it takes every day citizens like you to defend human rights.

Many people who have sought legal help for a violation during pregnancy or birth have been re-traumatized, 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 Rights Bar Association exists to help lawyers take cases, and do better when they do, but BRBA does not take clients as an organization. National Advocates for Pregnant Women rarely takes individual clients, and when they do, mainly focuses on criminal defense based on pregnancy or an outcome of pregnancy.

We are happy to be a resource, but we are unlikely to be able to take individual cases. We hope the resources here help you navigate these difficult issues with more confidence and tools.

#### **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. We hope to update it as we continue to learn what is helpful and needed, and based on the feedback we receive from you.

If you would like to get in touch with us to share your thoughts or to connect further, please contact us at: info@advocatesforpregnantwomen.org or info@birthrightsbar.org.

# MISTREATMENT AND ABUSE

The problem of mistreatment during childbirth is not new, but there have not been shared words, definitions, or categories until recently. Words like mistreatment, abuse, disrespect, violence and obstetric violence have been used.

Researchers from all over the world have been working to create shared categories so that mistreatment can be measured and fixed. They are still working on it and are still finding new ways of describing and talking about this issue.

Here are seven categories that researchers are using 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
- Blaming 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

- Being treated unfairly based on race, heritage or ethnic group
- Held back from discussing concerns because of feeling discriminated against
- Held back from discussing concerns or asking questions because the provider used language you did not understand
- Discrimination based on ethnicity/race/religion
- Discrimination based on age
- Discrimination based on socioeconomic status
- Discrimination based on HIV status

#### Failure to meet professional standards of care

- 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 process
- 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 women and providers

- Poor communication
- Held back from asking questions or discussing concerns due to disagreement with providers or fear
- 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**

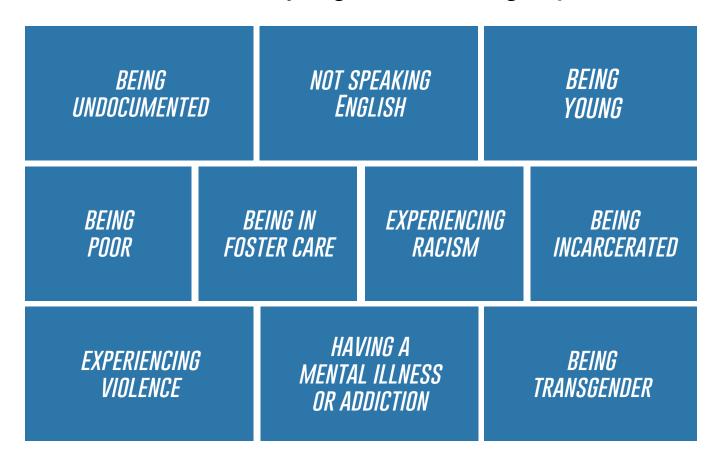
- Physical condition of facilities
- Staffing constraints
- Staffing shortages
- Supply constraints
- Lack of privacy
- · Lack of redress
- Bribery and extortion
- Unclear fee structures
- Unreasonable requests by health workers

We are sharing these examples to validate that this range of things is considered mistreatment or abuse during birth. What would you add or change in these lists? We would put "not being asked before procedures are done" in the "physicial abuse" category, in addition to where the researchers put it. See more about this in the Notes section at the end.

# **BARRIERS**

Everyone has human rights, whether those rights are protected by society, or the government, or not enforced at all. There are many ways pregnant and laboring people may face barriers to accessing their human rights. Or pregnant and laboring people 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 and Laboring People**



You may have more or less barriers to having your human rights protected or enforced during pregnancy or birth depending on how many of these other things you are also experiencing. Your options for advocating for yourself will also depend on these barriers. We hope this resource is helpful to many people but we know that that you may need to make adjustments to fit your situation.

# Section 2 BIRTH RIGHTS

And the scream around our belonging is our own long longing to be held.

And how it hurts to be fought for with just a few small tools while the whole world destroys us."

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

# I HAVE THE RIGHT TO...



Developed by Demetra Seriki, CPM and China Tolliver

# KNOW YOUR RIGHTS

# 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 is one that many people are working to see recognized, and there are key principles recognized in state and federal law.

#### What does this look like?

This means that 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 requiring a certain place of birth, though there are State laws restricting what some providers can do. 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 punishment or opposition.

#### 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 or, because they are not licensed in your jurisdiction, or State law limits their scope of practice. Facilities do have a right to say who can be in the facility which can mean 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 to change your mind. Providers may threaten to involve Child Protective Services (CPS) 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 child welfare consequences, especially for people who are more likely to targeted for State control, such as low-income women, women of color, or drug-using women.

#### I have the right to 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. If they do, they are violating their ethical duties and standard of care, and may be committing battery on you. Battery is a 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"--they are merely meant to document that you have received informed consent, which should be a conversation with your provider(s). 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 doesn't prove that you "consented" if you later expressed a lack of consent. But 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 women 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 decision-making process.

#### But there's more...

Sometimes providers will indicate that you do not have time to ask questions because there is a medical emergency. Even in an emergency, however, if you are competent then you have the right to information about all suggested procedures. We have noticed that families 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 required to contact CPS if they believe that your refusal of recommended procedures is abuse or neglect (even though providers often over-report to the detriment of the doctor-patient relationship).

#### 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, even for the sake of someone else (including their own children). 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 get better information and can make a thoughtful decision, without feeling pressure from providers or family members. Since some things during 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 be scared of 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 interpretation of the law. You may encounter coercion or consequences when you refuse a suggested procedure.

This is especially true for procedures recommended for your baby after birth. The U.S. Supreme Court has consistently recognized the right of parents to make parenting decisions, including medical decisions, but that right is qualified by governmental interest in the health and safety and the vulnerability of children. This means that health care providers are required to contact CPS if they believe that your refusal of recommended procedures puts your baby's health at risk such that it would constitute abuse or neglect. In spite of the lack of state jurisdiction over children who are not yet born, many providers and state courts wrongly believe they may force a pregnant person to receive treatment for their fetus.

# 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, or because you cannot pay. The medical facility has the obligation to stabilize a patient, and 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 that other 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.

#### 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, and it does not mean you can receive any kind of care. 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.

If you encounter or expect difficulty exercising 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 unfamiliar with the law surrounding rights in childbirth, please refer them to Birth Rights Bar Association or National Advocates for Pregnant Women for subject matter expertise.

<sup>\*</sup> The federal Emergency Medical Treatment and Labor Act (EMTALA) applies to hospitals that take Medicare payments and have dedicated emergency rooms, which is about 80% of hospitals. There are many websites where you can learn more about EMTALA.

# DRUG TESTING

Pregnant and postpartum people have the right refuse any medical procedure including a drug test, and they have the right to refuse any medical procedure on behalf of their children (with some exceptions related to child abuse and neglect prevention). Nonetheless, pregnant and postpartum women and their newborn babies are typically drug tested in medical settings without their knowledge or explicit, informed consent.

Positive toxicology results are too often reported to government officials or used to support criminal and civil child abuse or neglect prosecutions, custody decisions, and other non-medical 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 tissue. It does not indicate abuse or addiction, recency, frequency, or amount of use; or impairment."

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, 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 U.S., 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 as a factor in deciding whether to screen an infant for maternal illicit drug use."



### Clinical drug test results are not reliable and are not forensic evidence.

- A clinical drug test is an initial lab test done in a health care setting, and is 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 done 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 is why health care providers often start with a clinical drug test.



#### Clinical drug test results often show false positives.

A positive clinical test does not prove the patient was using a particular substance because
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 non-criminalized 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 one used a particular substance, without at least confirmatory testing.



### Drug tests may be conducted improperly or produce inaccurate results.

- Medical testing done without informed consent is improper and violates common law principles and medical ethics.
- Examples from across the U.S. and abroad demonstrate the risks of contamination in laboratories and the resulting errors in test results and reporting. For example, between 2005 and 2015, the Motherisk Laboratory at the Hospital for Sick Children in Toronto tested more than 24,000 hair samples for drugs and alcohol, from over 16,000 different individuals, for child protection purposes. The results were introduced as evidence in court and resulted in both temporary and permanent loss of custody of children. An independent review in 2015 found this testing was "inadequate and unreliable" for use in child protection and criminal proceedings.
- In Houston, Texas, a leaky roof damaged specimens held in a police lab, and a 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.



# "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, violates physicians' ethical responsibility and can deter people from obtaining prenatal and other healthcare during pregnancy. For those who are pregnant and actually have a substance use disorder, it can deter them from seeking treatment.
- That's why major 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 women based on drug use.
- The U.S. Supreme Court has ruled that it is unconstitutional to use the results of drug testing obtained in the guise of medical care for law enforcement purposes without informed specific consent to a search for evidence of a crime.

### KEY LEGAL AND ETHICAL PRINCIPLES

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 Department 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 caesarean 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."

In re Baby Boy Doe, 632 N.E.2d 326, 393 (Ill. App. Ct. 1994)

"[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."

Baby Boy Doe, 260 Ill.App.3d at 401, 198 Ill.Dec. at 273, 632 N.E.2d at 332.

"[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 \_\_\_(Ill. 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... Obstetriciangynecologists 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 Reoprt, A Human Rights Based Approach to Mistreatment and Violence Against Women in Reproductive Health Services With a Focus on Childbirth and Obstretric 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 125 Ill.2d 267, at 280 531 N.E.2d 355, 126 Ill.Dec. 60

# 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

# WHAT YOU CAN DO DURING A VIOLATION

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, their impact will likely be even greater. It is best to consider possible violations early and to come up with a plan about what you can do in the moment.

There is no definitive strategy that works every time in every situation, and some strategies come with risks. In particular, some people such as low-income women, immigrants, single women, youth, people of color, transgender and gender non-conforming people, people in foster care, and people who use drugs, may face harsher consequences for their resistance to authorities or may be targeted as a result of their being identified as part of 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.



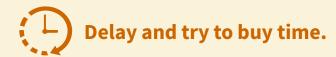
Make eye contact or hold someone's hand.



Get more information.



Focus on what you have the power to do.



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). 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 that sidesteps the violation (such as the baby being born).



### 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.

**Taking notes while things are happening is also a good idea.** Having a record that you made in real-time can help you process what happened. In addition, having 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 health care provider, "Is this being recorded in my chart?" or "Can you make sure this is documented in my chart?" (See Documentation form.)



#### 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 a translator.



#### 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, or 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 I 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.

# HOW TO BUY TIME WITH QUESTIONS



Questions developed by China Tolliver of Urban Doula

#### **Template Instructions**

#### **How to use "Acknowledgement of Informed Consent"**

This form can be used to buy time when trying to refuse a procedure when a provider is pressuring or threatening you. You may consider asking them to sign this document relieving them from responsibility for your informed decision.

(See page 30)

#### How to use "Documentation"



Add a title, such as "My Labor Notes" or "Client X 2020"



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

Date	Time	Who/What/When/Where
2/21/20	10:50am	Example: In room w/ Mrs. 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."

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

(See page 31)

#### **Acknowledgement of Informed Consent**

I,, have been informed of what my	
	, explained as serious risks to myself and my
	do not consent to
I have conside	red that information and I am nevertheless <i>consciously and</i>
conscientiousl	y declining the procedure and/or intervention at this time. I will let
my provider kr	now if I change my mind. I accept full responsibility for my decision
based on the i	nformation 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 ref	use medical interventions.
Date: _	Time
Signature: _	
Signature of w	itness (optional):

#### **Documentation**

Date Time Who/What/When/Where	

# PREGNANT PEOPLE WHO ARE USING DRUGS OR ALCOHOL HAVE RIGHTS

People who use drugs or alcohol or have a history of substance abuse or a substance use disorder may face additional barriers to respectful health care and freedom from violations during pregnancy and labor. Examples of this include: being told you can't have pain relief during labor, being told to stop medication assisted treatment during pregnancy or lactation, being drug tested without consent, or having your confidential medical information shared.



#### Even if I am using drugs or alcohol, I have the right to...

- receive medications that are helping me, including medication-assisted treatment for substance use.
- be administered pain relief during labor.
- prevent law enforcement from accessing my medical records and exams without my consent.
- maintain confidentiality in my medical records, including any history of substance use treatment.
- receive information about the risks, benefits and alternatives of various procedures or treatments, including drug tests.
- refuse treatments, tests, or medical procedures.
- be treated with respect and dignity.
- remain silent and not speak to the police.



Do not speak to the police without a lawyer present.

If you are facing criminal charges, contact NAPW 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."

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

# HOW TO SAY: "WHAT HAPPENED TO ME WAS NOT OKAY"

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. There is no requirement that you or your support person make a report or complaint about a violation. It is totally 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, describe in clear steps how to carry out each one, 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.



Write your narrative.



Give direct feedback.



File a formal complaint.



Work the system, be creative.



Contact a State representative.



Contact the media.



Take direct action.



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

#### BENEFITS

 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.  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.



#### **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 BENEFITS It can be traumatic to remember and write It can be cathartic. Writing everything down what happened. The process can stir down can help you release your story so you feel freer to attend to other life tasks. It up strong emotions that extend beyond the time of writing. 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.



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

Refer to your narrative. Start a new document that is intended to be shared that is professional and 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. Get some feedback. Make edits. In your final version, include a formal address block and salutation, type it, and print it. Send it by postal mail with delivery confirmation.

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: for example, the provider's boss, or someone the provider collaborates with. Recommended Google search words: formal letter template.

## COSTS BENEFITS The person might reflect on your feedback Whenever you communicate with someone regarding a vulnerable issue, it can feel and learn from it. stressful and hard. You may never receive a The person might become aware of response, which can add to the emotional something they not previously considered or been informed of. The person might choose to make a Once delivered, the letter may be shared. It might even be placed in your medical change in how they practice that improves the care they provide. You might be labeled a "difficult patient." It will take time to write and edit. The cost of postage.



## 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 regulates 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 Omsbud.
- 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. The Joint Commission for hospitals, or the Commission for the Accreditation of Birth Centers .
- Accredited credentials like the "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 and civil rights violations. Recommended Google search terms: consumer complaint [Name of State] or civil rights complaint [Name of State], and look for sites ending in .gov.

## COSTS BENEFITS

- Your time and the cost of any computer/ internet access or postage that is necessary.
- 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.
- 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.



## Work the system, be creative.

## **ACTION STEPS**

You may understand the system you're in well enough already to know of other ways to get 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 get 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've spoken to a mental health worker who knew that calling 911 from within a health care 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, and she was supported in her medical decision-making 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 lots of people to a public location to take collective action (see "Take Direct Action"). You can use your creativity to come up with new solutions that no one has considered before.

### COSTS

## 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.

- Police involvement in particular, can add additional trauma, and 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.

## BENEFITS

- Trying something new could lead to a breakthrough.
- You could change the dynamic in your favor, even if only temporarily.
- You could get other people in positions of leadership involved.
- You could show that you have tried many things, and could inspire others to join you or take interest.



## **Contact a State representative.**

## **ACTION STEPS**

The person who experienced the violation is best positioned to make this outreach, but others who were present may do so as well (with consent).

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 mail a letter to the address nearest you 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.

## BENEFITS COSTS Your time and the cost of any computer/ May lead to an investigation by another internet access or postage that is state agency. May lead to your previous complaint being necessary. The feeling of discouragement that may acted upon. result from taking time and then hearing May lead to the representative being more nothing or seeing no action taken. aware. Official records could become evidence May lead to the representative supporting in subsequent legal cases. The risk is that or offering legislation that could change whatever you say in the complaint could be policy. used to attack your credibility in a future legal proceeding.



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 tweet about these issues. 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

## BENEFITS

- 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 picks 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 as aspects you want highlighted.
  Your statements might be taken out of
  context. If the media publishes something,
  it can be accessible indefinitely, you can't
  take it down.
- 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.



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 support spaces to share with people who've 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
This is an indirect way to approach your specific harm, it takes time, and progress is slow.	<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've had a similar experience.</li> </ul>



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, for any number of reasons but 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 Lawsuits cost money, even if you are able The offending party is forced to respond in to spread out and recoup the costs. some way. Even with the services of an attorney, a Information may come to light that might lawsuit can take a lot of your time and last not otherwise be revealed. Money damages might be recovered. many years. • Without an attorney, a lawsuit requires the The facility might make policy changes in amount of attention of at least a part-time response to the lawsuit. A lawsuit might lead to settlement iob. negotiations. Any lawsuit carries the risk of losing, or even that a loss might create bad While it cannot undo the harm suffered, and precedent for future cases. never truly make you whole, it might still be A lawsuit puts the facility and provider in empowering to assert your rights publicly a defensive position and may render them and in court. less likely to talk or negotiate, at least in the near term.

## HOW TO ACCESS YOUR MEDICAL RECORDS

Having 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 have better understanding of what happened from the provider or facility point of view. Your records may also reveal inconsistencies in 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 a hold of your records can be important and useful. This document is intended to help you understand what the process for requesting your records is and what to expect.

You have the right to see and get 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 special staff person whose job is to ensure they are complying with the law. States also have laws that give you rights to your medical records. These State laws have to be as good or better 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 the law you can be charged a fee for copying your records, but the fee has to 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 says 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 find the HIPAA compliance officer or privacy officer for the facility and give them a call.



## Review your records.

When you look at your records it can be confusing at first. Unless you are used to reading medical records, you may not know where to look or how to read it. 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 then look up those abbreviations online, or contact your provider. Once you decode one or two abbreviations or special words it can make a lot of things make more sense.

Ultimately, you may need to have a medical expert look at your records to help you understand. If you are considering a lawsuit eventually a medical expert will 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 to have corrected, contact the provider or facility and ask them what their process is. There is no standard process. But 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 refuse 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 denial to correct your records is unjust or may harm you (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 Federal Department of Health and Human Services.

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

## HOW TO FIND AND AFFORD A LAWYER

## **Fees**

Legal fees vary widely; don't be surprised if your attorney charges from \$150-\$500 per hour. Rates vary by specialty, experience, region, and business model. Lawyers also use different fee arrangements from hourly to "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 issue.

"Legal aid" programs offer inexpensive or free legal services to those in need using special guidelines for eligibility, often based on where you live, the size of your family, and your income. Some cities have non-profit organizations that provide legal services for specific issues. If you have such an organization in your area, consider asking them to take 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. Generally, for non-criminal cases there is no 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 and ask a clerk what support the court can provide for pro se litigants. Departments and agencies of both the state and federal governments often have 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.

## 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 Rights Bar Association 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 BRBA to ensure that the unique issues related to childbirth are considered.

## APPROACHING A LAWYER

This resource is for individuals seeking to bring a legal case to redress a violation of rights during birth. This 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 the statute of limitations in your state.

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 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, and you will not be permitted to file the claim no matter how strong your case is or how bad your injuries are.

A legal case is not the only pathway to redress harms. You can also file formal complaints against the facility or providers, or organize for change through advocacy and with community groups.

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 cases in this area:

- <a href="https://www.independent.co.uk/news/long">https://www.independent.co.uk/news/long</a> reads/childbirth-delivery-room-ethics-doctor-patient-healthcare-a8085346.html
- https://www.yahoo.com/news/woman-sues-hospital-for-traumatic-birth-that-201605478.html
- <a href="https://www.nytimes.com/2014/05/17/nyregion/mother-accuses-doctors-of-forcing-a-c-section-and-files-suit.html">https://www.nytimes.com/2014/05/17/nyregion/mother-accuses-doctors-of-forcing-a-c-section-and-files-suit.html</a>

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, 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 Rights Bar Association**, 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. **National Advocates for Pregnant Women** 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.

inank you for your consideration,
[Name and contact information]

. .

## 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 until a long time after the experience. Even just being a witness to 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 by compounded by previous traumas.

## **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 can also ask 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.

## **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," "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.

There are numerous online resources and new ones are frequently being posted. Use your judgment, 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," "trauma recovery" will help you find these resources.

Some enduring websites on pregnancy loss include: American Pregnancy Association, BabyLoss, Dr. Berman's Hygeia Foundation, the MISS Foundation, and 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, the National Institute of Mental Health, the Anxiety and Depression Association of America, and the National Perinatal Association.

## Resources for people who have substance use disorders

Postpartum can be a particularly vulnerable time for people who have history of substance abuse or a substance use disorder, especially if there is new trauma to deal with. Finding treatment providers who are knowledgable 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 authorites. It may be best to try and find trustworthy and effective providers through word of mouth. When researching providers ask if they have a "harm reduction" approach. Contacting groups such as Vocal NY, The 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 also has some great resources on substance use related to pregnancy.

The Substance Abuse and Mental Health Services Administration has a resource that is supposed to help people find treatment. However, the fact is, 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 TOWARD BIRTH JUSTICE

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: Findina Ceremony

## MOVING TOWARD BIRTH JUSTICE

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 people with the capacity for pregnancy. 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 part of reproductive justice. 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. As 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 the 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 seeks to fill that gap.

Like reproductive justice, birth justice is about more than quality health care during birth and about more than the rights of people giving birth. Birth justice recognizes that in order for people to get respectful, appropriate health care, and have their rights recognized, 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 HEALTH CARE

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.

## PERINATAL RIGHTS

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.

## **BIRTH JUSTICE**

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 white men. Inequality compromises perinatal health in many different ways. Challenging inequality is necessary for birth justice.

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 Is 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, sexism, classism, ableism, or xenophobia 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 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.

To fully actualize birth justice entails moving the voices and organizations of people who've experienced things such as racism, homophobia, sexism, classism, ableism, or xenophobia to the center of our minds, conversations, and priorities. This is important so that 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.

## Section 6 RESOURCES

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

## A note on terms

We use gender-inclusive language throughout this resource, including the terms "pregnant person" and "birthing person," in order to acknowledge and affirm that not everyone who gets pregnant or gives birth is a woman, although these terms do include pregnant women.

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.

## **Definitions**

"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.

**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."

**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.

- a. False positive the results incorrectly indicate the presence of a chemical
- b. Forensic test a drug test carried out in order to provide legal evidence.
- c. Positive toxicology test results indicating the presence of a chemical in the sample.
- d. 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. ressuring, 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 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. Possession, or in pregnancy sometimes use, of drugs that can lead to arrest and/or criminal charges.

**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.

**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.

**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 oftengiven 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. Kimberle 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.

**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.

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, the requirements for licensing may 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.

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

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.

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

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

**Right to privacy** – The United States 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.

**State representative** - someone who was elected to serve in Congress or the Senate. 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.

**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.

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

## CONNECTIONS

## **Allied Organizations**

Academy of Perinatal Harm Reduction

**All Options** 

A Mother's Choice

**Ancient Song Doula Services** 

Birthmark Doula Collective

Birth Monopoly

Black Mamas Matter Alliance

Center for Optimal Living

Citizens for Midwifery

**Elephant Circle** 

**Every Mother Counts** 

Forward Together

Groundswell Birth Justice Fund

Harm Reduction Coalition

Harm Reduction Therapy

If/When/How

Improving Birth

International Cesarean Awareness Network

Michigan Prison Doula Initiative

National Association for the Advancement of Black Birth

National Birth Equity Collaborative

National Black Doulas Association

National Partnership for Women and Families

National Perinatal Association

National Perinatal Task Force

Public Citizen

Radical Doula

Rise Up Midwife

SisterSong

Vocal NY

We Rise! Leadership Collective Minnesota

White Ribbon Alliance

## **About Us**



National Advocates for Pregnant Women (NAPW) is a non-profit organization that combines pro-bono criminal defense, advocacy, public education and organizing to ensure no one is locked-up, shamed, or denied constitutional or human rights because they have the capacity for pregnancy, are pregnant, or because of any outcome of pregnancy - including abortion, miscarriage, stillbirth and birth.

http://www.advocatesforpregnantwomen.org/



Birth Rights Bar Association (BBBA) is dedicated to promoting rights associated with childbirth, including physical liberty, bodily integrity, autonomy, privacy, due process, equal protection, religious liberty, and informed consent. We work to promote these rights by building skills and networks among legal professionals and providing public education.

https://birthrightsbar.org/

You are welcome to reach out to us if you have questions or need help at: <a href="mailto:info@advocatesforpregnantwomen.org">info@advocatesforpregnantwomen.org</a> or <a href="mailto:info@birthrightsbar.org">info@birthrightsbar.org</a>

## **Find More**

### **Doulas**

To find a doula try searching "Your State + doula + association"

- https://radicaldoula.com/becoming-a-doula/doula-trainings/
- https://transform.childbirthconnection.org/action/consumeradvocate/cbe-doula/
- https://doulamatch.net/national-and-local-doula-certifying-organizations.aspx
- https://blackdoulas.org/

### **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:

https://groundswellfund.org/birth-justice-fund/

## ADDITIONAL NOTES

## **Section 1: Introduction**

For more on maternal mortality or other failures of the U.S. health care system during pregnancy and birth we recommend Nina Martin's reporting as a place to start: https://www.propublica.org/people/nina-martin and for more policy oriented material we recommend Maternity Care in the United States: We Can - and Must - Do Better available at: <a href="maternative-care-in-the-united.pdf">nationalpartnership.</a> org/our-work/resources/health-care/maternity-care-in-the-united.pdf

### Page 8: Mistreatment and Abuse

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" available here: <a href="https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-019-0729-2">https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-019-0729-2</a> and "The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review" available here: <a href="https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001847">https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001847</a>

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" at: <a href="https://birthmonopoly.com/obstetric-violence/">https://birthmonopoly.com/obstetric-violence/</a>

## **Section 2: Birth Rights**

### Page 13. Rights Over My Birth

Rights Over My Birth... we developed this material with the help of two birthworker activists, Demetra Seriki (<a href="https://www.riseupmidwife.com/">https://www.riseupmidwife.com/</a>) and China Tolliver (<a href="https://amcmbirth.com/">https://amcmbirth.com/</a>).

### Page 14. Know Your Rights

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, available at: <a href="https://abovethelaw.com/2020/04/covid-19-surrogacy-and-birthing-alone/?rf=1">https://abovethelaw.com/2020/04/covid-19-surrogacy-and-birthing-alone/?rf=1</a>

Several other organizations have also attempted to outline these rights.

- https://www.whiteribbonalliance.org/rmctoolkit
- https://birthmonopoly.com/
- http://www.nationalpartnership.org/our-work/resources/health-care/maternity/the-rights-of-childbearing-women.pdf
- https://www.ifwhenhow.org/resources/birthing-rights/

## Page 18. Drug Testing

Citations for this fact sheet can be found at: <a href="http://advocatesforpregnantwomen.org/main/publications/fact\_sheets/clinical\_drug\_testing\_of\_pregnant\_women\_and\_newborns.php">http://advocatesforpregnantwomen.org/main/publications/fact\_sheets/clinical\_drug\_testing\_of\_pregnant\_women\_and\_newborns.php</a>

We have also compiled statements from public health and medical groups against the punishment of pregnant women here at: <a href="http://advocatesforpregnantwomen.org/main/publications/fact\_sheets/medical\_and\_public\_health\_group\_statements">http://advocatesforpregnantwomen.org/main/publications/fact\_sheets/medical\_and\_public\_health\_group\_statements</a> opposing prosecution and punishment of pregnant women revised june 2018.php

## Page 21. Key Legal and Ethical Principles

The listed citations should be easy to search for with the information provided.

The U.N. Report on Obstetric Violence is available in multiple languages at: <a href="https://digitallibrary.un.org/record/3823698?ln=en">https://digitallibrary.un.org/record/3823698?ln=en</a>

## **Section 3: During a Violation**

## Page 32. Pregnant People Who Use Drugs or Alcohol Have Rights

The Harm Reduction Coalition has created a "Pregnant People Who Use Drugs Toolkit" available at: <a href="https://harmreduction.org/">https://harmreduction.org/</a>

The following organizations may also be helpful:

- <a href="https://www.perinatalharmreduction.org/">https://www.perinatalharmreduction.org/</a>
- http://www.vocal-ny.org/
- http://centerforoptimalliving.com/
- <a href="https://harmreductiontherapy.org/">https://harmreductiontherapy.org/</a> (for support or referrals)
- <a href="http://www.nationalperinatal.org/Substance">http://www.nationalperinatal.org/Substance</a> Use (for resources on substance use related to pregnancy)

## **Section 4: After a Violation**

### Page 34. How To Say: "What Happened To Me Was Not Okay"

Public Citizen has a great resource for making complaints related to health care at: <a href="https://www.citizen.org/article/">https://www.citizen.org/article/</a>
<a href="physician-accountability/">physician-accountability/</a>

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 at: <a href="https://birthmonopoly.com/obstetric-violence/obstetric-violence-map/">https://birthmonopoly.com/obstetric-violence/obstetric-violence-map/</a>
- Elephant Circle is tracking violations stemming from COVID-19 at: <a href="https://www.elephantcircle.net/report-violations">https://www.elephantcircle.net/report-violations</a>
- Center for Reproductive Rights also collects information about rights violations at: <a href="https://reproductiverights.org/form/report-violations">https://reproductiverights.org/form/report-violations</a>

Other descriptions of the complaint-making process have been done by these organizations:

- https://improvingbirth.org/resources/
- <a href="http://cfmidwifery.org/Resources/item.aspx?ID=1">http://cfmidwifery.org/Resources/item.aspx?ID=1</a>
- http://www.ican-online.org/wp-content/uploads/2014/06/filing-a-hospital-complaint.pdf

You can identify your elected representatives through any of the following sites:

- https://www.congress.gov/state-legislature-websites
- https://openstates.org/
- https://www.commoncause.org/find-your-representative

## Page 44. How to Access Your Medical Records

You can file a complaint of a HIPAA violation here: <a href="https://www.hhs.gov/hipaa/filing-a-complaint/complaint-process/">https://www.hhs.gov/hipaa/filing-a-complaint/complaint-process/</a> index.html

## Page 47. How to Find and Afford a Lawyer

State bar associations are a good place to start a search for an attorney. The American Bar Association also has recommendations at: https://www.americanbar.org/groups/legal\_services/flh-home/flh-hire-a-lawyer/

## Page 50. Mental Health Support After Experiencing Violence or Mistreatment

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

A specific strategy for dealing with trauma is available at: <a href="http://www.nationalcenterdvtraumamh.org/wp-content/uploads/2012/01/Fingerhold-Practice-for-Managing-Emotions-Stress-Final.pdf">http://www.nationalcenterdvtraumamh.org/wp-content/uploads/2012/01/Fingerhold-Practice-for-Managing-Emotions-Stress-Final.pdf</a>

### Several organizations provide support for all kinds of situations:

- https://www.all-options.org/
- <a href="https://traumastewardship.com/">https://traumastewardship.com/</a>
- <a href="https://www.marchofdimes.org/complications/dealing-with-grief-after-the-death-of-your-baby.aspx">https://www.marchofdimes.org/complications/dealing-with-grief-after-the-death-of-your-baby.aspx</a>
- https://traumainformedoregon.org/
- http://www.nationalcenterdvtraumamh.org/
- <a href="http://centerforoptimalliving.com/">http://centerforoptimalliving.com/</a>
- <a href="http://www.nationalperinatal.org/Substance\_Use">http://www.nationalperinatal.org/Substance\_Use</a>

## **Section 5: Moving Toward Birth Justice**

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, available at: <a href="http://bit.ly/fundequity">http://bit.ly/fundequity</a> and "A New Vision for Advancing Our Movement for Reproductive Health, Reproductive Rights, and Reproductive Justice," available at: <a href="https://forwardtogether.org/tools/a-new-vision/">https://forwardtogether.org/tools/a-new-vision/</a>

### Many online resources exist for learning about implicit bias, systemic oppression, racism:

- <a href="https://implicit.harvard.edu/implicit/https://nationalequityproject.org/resources/featured-resources/lens-of-systemic-oppression">https://implicit.harvard.edu/implicit/https://nationalequityproject.org/resources/featured-resources/lens-of-systemic-oppression</a>
- https://rewire.news/article/2018/04/11/maternal-health-replace-race-with-racism/
- <a href="https://journalofethics.ama-assn.org/article/structural-competency-meets-structural-racism-race-politics-and-structure-medical-knowledge/2014-09">https://journalofethics.ama-assn.org/article/structural-competency-meets-structural-racism-race-politics-and-structure-medical-knowledge/2014-09</a>

## To learn more about Reproductive Justice, see:

- https://blackmamasmatter.org/wp-content/uploads/2018/12/BMMA-PolicyAgenda-Digital.pdf
- https://forwardtogether.org/tools/
- <a href="https://www.sistersong.net/reproductive-justice">https://www.sistersong.net/reproductive-justice</a>
- https://latinainstitute.org/

## Finally, to learn more about Birth Justice, see:

- https://forwardtogether.org/we-need-doula-care-to-achieve-reproductive-justice/
- http://www.elephantcircle.net
- <a href="https://everymothercounts.org/wp-content/uploads/2019/03/Advancing-Birth-Justice-CBD-Models-as-Std-of-Care-3-25-19.pdf">https://everymothercounts.org/wp-content/uploads/2019/03/Advancing-Birth-Justice-CBD-Models-as-Std-of-Care-3-25-19.pdf</a>
- https://radicaldoula.com/the-radical-doula-guide/
- <a href="https://www.blackwomenbirthingjustice.org/about">https://www.blackwomenbirthingjustice.org/about</a>
- https://www.ancientsongdoulaservices.com/

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## USE OF FORCE









## ONLY A COURT ORDER CAN FORCE YOU.

Court orders can be challenged. Court orders can be wrong. Do not assume that they can get a court order or start a child welfare case, even if they threaten to. Seek out your own counsel for medical and legal questions.

## **Birth Rights**

A resource for every day people to defend human rights during labor and birth

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