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Law in the Time of Zika

DISABILITY RIGHTS AND REPRODUCTIVE JUSTICE COLLIDE

Seema Mohapatra[†]

INTRODUCTION

Jennelle, a twenty-four-year-old who lives in Miami, develops a fever and a rash. She makes an appointment to see Dr. Davila, her family physician. Given her symptoms, Dr. Davila is concerned that Jennelle may have contracted Zika when she traveled to Brazil for a recent visit. Dr. Davila asks Jennelle if she may be pregnant, and she admits that it is possible, as she is not using any birth control. Jennelle's urine is tested, and she is indeed pregnant. Although the pregnancy is unplanned, Jennelle is excited about having a baby. Dr. Davila recommends testing for Zika due to her symptoms and recent travel. Dr. Davila explains to Jennelle that if she tests positive for Zika, her fetus may face a risk of microcephaly, which is characterized by a smaller than typical brain and head. Jennelle is very scared by this possibility but agrees to be tested. Jennelle's Zika test comes back a few days later, and Dr. Davila calls her to tell her it is positive. Jennelle asks Dr. Davila "What does this mean?"¹

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¹ This hypothetical demonstrates a common scenario faced by doctors in the height of the Zika epidemic. Physicians often were not sure what kind of advice to give in this scenario. One physician practicing in Miami noted that "[p]hysicians like me are learning about Zika along with our patients. This takes a dose of humility on our part

What should Dr. Davila say? Should he follow the guidance provided to physicians by the Centers for Disease Control (CDC) about taking care of pregnant Zika patients? If so, it would look like this:

Dr. Davila tells Jennelle he needs to see her more often in the office to monitor her pregnancy with frequent scans to see how the fetus is developing. Dr. Davila explains that amniocentesis² is available to her but carries with it both the possibility of miscarriage and false negatives and false positives. He explains that ultrasounds will be the best way to monitor the fetus to see if the fetus develops any Zika related anomalies.

Although Dr. Davila's advice and actions follow the CDC's guidance to physicians in caring for pregnant women with Zika,³ reproductive rights activists and disability rights advocates would both criticize this hypothetical. Reproductive rights advocates would note that Dr. Davila should mention the alternative of pregnancy termination so Jennelle knows that is an option. Disability rights activists would argue that such a standard is eugenic in nature, that it pushes a view that a fetus that is not absolutely perfect should be terminated, and that if pregnancy termination is not mentioned in other cases, Dr. Davila should not discuss it here. Rather, Dr. Davila should assuage Jennelle's fears by giving her information about support organizations that may help her learn about raising a child with a birth defect, such as microcephaly.⁴ Decidedly, there are numerous other issues in the hypothetical to be analyzed, but it

and an understanding from our patients that we learn something new every single day.” See Christine Curry, *I'm a Doctor Treating Pregnant Women with Zika and This Is What It's Like*, GUARDIAN, (Aug. 8, 2016, 10:17 EDT), <https://www.theguardian.com/commentisfree/2016/aug/08/zika-doctor-pregnant-women-obgyn-florida> [<https://perma.cc/8AKP-5KKM>].

² Amniocentesis is defined as “a procedure in which amniotic fluid is removed from the uterus for testing or treatment.” *Amniocentesis*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/amniocentesis/about/pac-20392914> [<https://perma.cc/6D86-4BBW>].

³ Titilope Oduyebo, et al., *Update: Interim Guidance for Health Care Providers Caring for Pregnant Women with Possible Zika Virus Exposure—United States (Including U.S. Territories)*, JULY 2017, 66 MORBIDITY & MORTALITY WKLY. REP. 781 (2017), https://www.cdc.gov/mmwr/volumes/66/wr/mm6629e1.htm?s_cid=mm6629e1_w [<https://perma.cc/55DZ-ET8Z>] (Dr. Davila has followed the CDC guidelines which provide that “[f]or pregnant women with laboratory evidence of possible Zika virus infection, serial fetal ultrasounds (every 3–4 weeks) should be considered to assess fetal anatomy, particularly fetal neuroanatomy, and to monitor growth.”).

⁴ See Cara T. Mai et al., *Public Perception of Birth Defects Terminology*, 94 BIRTH DEFECTS RES. (PART A): CLINICAL & MOLECULAR TERATOLOGY 984, 984–89 (2012) <http://onlinelibrary.wiley.com/doi/10.1002/bdra.23080/abstract;jsessionid=4F0490474342C1AD0A4DF37A5DAE7086.f04t03> [<https://perma.cc/DX8Q-VZQ2>] The most common lay term for a child born with microcephaly is “birth defect.” *Id.* at 984. Recent survey results show that over 20% of Americans find the term offensive, but that it is the most preferred term by all survey participants. *Id.* Although the term may be offensive to some, it is the most common and easily understood term to describe a congenital anomaly.

is introduced here to demonstrate how disability rights and reproductive rights often clash at the patient's bedside.

This conflict is one of the tensest in current and future reproductive theorizing. This article attempts to trace this conflict in various regulatory and real-life, clinical interactions. It highlights the need to detail how activists and regulators should be thinking about the intersection of reproductive justice and disability. This article is the first to examine medical and public health professional organizations' guidance papers related to Zika as a way to illuminate the tensions between reproductive rights and disability rights. The article also uses the Zika case study in a novel manner to show the importance of intertwining the public health goals of primary prevention and harm reduction.

The article proceeds as follows: Part I describes the government and activist responses to the recent and ongoing Zika outbreak to demonstrate a recent example of the tension between reproductive rights and disability rights. Part II explains the basic tenets of reproductive rights and the disability rights perspective. This Part suggests that a reproductive justice frame may be more helpful because it allows a woman options to decide whether or not to terminate a pregnancy but also provides support for parenting a child, if the woman chooses to do so. This part of this article draws attention to tensions between reproductive rights and disability rights in activism and in the courts, using the recent disability-selective abortion bans. Part III focuses on the role of the physician in navigating these conflicts and how public health guidance informs that role. This Part explains how although a woman's autonomy is paramount, the physician plays an important role in providing information to a woman on which she will base her decision. This Part also reviews the physician guidance issued by: The World Health Organization (WHO),⁵ an international public health entity;⁶ the Centers for Disease Control (CDC),⁷ the public health agency in the United States;⁸ and the American College of Obstetrics and Gynecology (ACOG)⁹ about how to care for pregnant women who may have contracted Zika. The analysis of such guidance suggests that they are incomplete in terms of both reproductive justice and disability

⁵ WORLD HEALTH ORG., <http://www.who.int/en/>. [<https://perma.cc/7UAR-GAMT>].

⁶ *About WHO*, WORLD HEALTH ORG., *ABOUT WHO*, <https://www.who.int/about/what-we-do/en/> [<https://perma.cc/6TW2-C67U>].

⁷ CTRS. FOR DISEASE CONTROL, <https://www.cdc.gov> [<https://perma.cc/78Z4-F75A>].

⁸ *Mission, Role, and Pledge*, CTRS. FOR DISEASE CONTROL (Apr. 14, 2014) <https://www.cdc.gov/about/organization/mission.htm> [<https://perma.cc/E2Z9-QEK7>].

⁹ THE AM. COLL. OF OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org> [<https://perma.cc/NX97-YTKB>].

rights. In order to incorporate both reproductive and disability rights, physician guidance should include counseling about raising a child with a disability.

Part IV of this article suggests that physician guidance in the Zika context must include a discussion of disability, in addition to reproductive options such as abortion, adoption, and continuation of the pregnancy. I provide examples of federal and state legislation that exist to help medical decision making. The language used in counseling is very important and impacts how patients perceive their options.¹⁰ I suggest a template that could be used by ACOG. The sample language combines language from state legislation in its standard of care for counseling pregnant patients with Zika.¹¹ This would harmonize and bolster both reproductive justice and disability rights values, and women would have more accurate and complete information while facing this difficult decision. Physician guidance should include counseling about raising a child with a disability.

I. CASE STUDY: THE ZIKA CRISIS

Prior to early 2016, most lay individuals had not heard of the Zika virus.¹² After an outbreak in Latin America, however, Zika panic seemed to take hold in the United States.¹³ Though the frenzy seems to have lessened in North America, between 2015 and 2018, 2,490 pregnant women in the United States and the District of Columbia tested positive for the Zika virus infection, with the number going up to 4,917 if one includes U.S. territories such as Puerto Rico.¹⁴ However, the panic has spread even further

¹⁰ See Titilope Oduyebo, et al., *Update: Interim Guidelines for Health Care Providers Caring for Pregnant Women and Women of Reproductive Age with Possible Zika Virus Exposure—United States, 2016*, 65 MORBIDITY & MORTALITY WKLY. REP. 122, 126 (2016) (highlighting the importance of physicians discussing exposures risks, plans and options with Zika with patients).

¹¹ See discussion *infra* note 270.

¹² Ed Cara, *Is The Zika Virus Causing Birth Defects In Brazil?*, MEDICAL DAILY, 2015 WLNR 36283641 (Dec. 7, 2015) (“Named after the forest it was first found in, Zika,” was once ignored and lacked the attention “garnered [by] other mosquito-borne viruses.”); *Zika Virus: Key Facts*, WORLD HEALTH ORG. (July 20, 2018), <http://www.who.int/mediacentre/factsheets/zika/en/> [<https://perma.cc/ES83-Q78P>], (“Zika virus . . . was first identified in Uganda in 1947 in monkeys,” and was subsequently “identified in humans in 1952 in Uganda and the United Republic of Tanzania. Outbreaks of Zika virus disease have been recorded in Africa, the Americas, Asia and the Pacific.”); Sandrine Ceurstemont, *Zika Virus Outbreak: What You Need to Know*, NEW SCIENTIST, (Feb. 4, 2016), <https://www.newscientist.com/article/2076386-zika-virus-outbreak-what-you-need-to-know/> [<https://perma.cc/EDB4-3VBZ>] (“The Zika virus was virtually unheard of until recently.”).

¹³ See Nathan D. Grubaugh & Kristian G. Andersen, *Navigating the Zika Panic*, 5 F1000RESEARCH 1914, *3–5 (2016) (discussing the public panic about the Olympics in Brazil and the spread of Zika).

¹⁴ *Pregnant Women with Any Laboratory Evidence of Possible Zika Virus Infection, 2015–2018*, CTRS. FOR DISEASE CONTROL & PREVENTION (Nov. 27, 2018),

around the globe with some countries, such as India, currently facing a Zika epidemic.¹⁵ As of October 2018, Zika infection can be found in ninety-six countries.¹⁶ The first Zika panic occurred when reports came out of Brazil that an increased number of babies were born with microcephaly, and that these babies were born to women with Zika.¹⁷ This connection had not previously been made with Zika infection.¹⁸ Although the symptoms of Zika in the women were often mild, this correlation with microcephaly led to travel advisories and alarm bells for pregnant women in Brazil and other countries where the Zika virus was prevalent.¹⁹ There was a growing panic all over the world about the potential spread of the virus and what harm it may cause.²⁰ The media contributed to this frenzy by featuring pictures of infants born with smaller than typical heads with offensive headlines about “brain-damaged babies.”²¹ In fact, many infants with microcephaly develop similarly to those without the condition and do not suffer from decreased IQ or other brain malfunctions.²² Although the rise of microcephaly and its connection to Zika is a cause for

<https://www.cdc.gov/pregnancy/zika/data/pregwomen-uscases.html> [https://perma.cc/79W9-986M].

¹⁵ Swati Gupta, *Zika Spreads Rapidly In India, with 94 Cases Confirmed*, CNN (Oct. 17, 2018, 9:36 AM), <https://www.cnn.com/2018/10/17/health/india-jaipur-zika-outbreak-rapid-increase-intl/index.html> [http://perma.cc/HY72-9VD6].

¹⁶ *Zika Travel Information*, CTRS. FOR DISEASE CONTROL & PREVENTION, (Aug. 14, 2018), <https://wwwnc.cdc.gov/travel/page/zika-travel-information> [https://perma.cc/XN7P-YUFL].

¹⁷ Jernej Mlakar et al., *Zika Virus Associated with Microcephaly*, 374 NEW ENG. J. MED. 951, 956 (2016), <http://www.nejm.org/doi/full/10.1056/NEJMoa1600651#t=articleTop> [https://perma.cc/8FYZ-DSCS]; Eric J. Rubin et al., Editorial, *Zika Virus and Microcephaly*, 374 NEW ENG. J. MED. 984, 984–85 (2016), <http://www.nejm.org/doi/full/10.1056/NEJMe1601862> [https://perma.cc/9AE2-N699].

¹⁸ See Mlakar et al., *supra* note 17; Rubin et al., *supra* note 17.

¹⁹ *Zika Virus Infection—Brazil and Colombia*, WORLD HEALTH ORG. (Oct. 21, 2015), <https://www.who.int/csr/don/21-october-2015-zika/en/> [https://perma.cc/RRR8-RSUD].

²⁰ Grubaugh & Andersen, *supra* note 13, at *3–5.

²¹ Maggie Fox, *Zika Virus Damages Babies' Brains After Birth, Doctors Report*, NBC NEWS (Nov. 22, 2016, 3:40 PM EST), <https://www.nbcnews.com/storyline/zika-virus-outbreak/zika-virus-damages-brains-after-birth-doctors-report-n687306> [https://perma.cc/QX7K-GBBE]; Donald G. McNeil Jr., *How the Response to Zika Failed Millions*, N.Y. TIMES (Jan. 16, 2017), <https://www.nytimes.com/2017/01/16/health/zika-virus-response.html> [https://perma.cc/488E-5V9G] (“[A] wave of brain-damaged babies is now being born. Their families are already suffering, and their medical care will eventually cost hundreds of millions of dollars.”); Donald G. McNeil Jr. & Pam Belluck, *Extensive Brain Defects Seen in Babies of Mothers with Zika*, N.Y. TIMES (Dec. 13, 2016), <https://www.nytimes.com/2016/12/13/health/zika-virus-baby-brain-defects.html> [https://perma.cc/4CPZ-GNZG]; Liz Szabo, *Report Paints Heartbreaking Picture of Zika-Linked Birth Defects*, USA TODAY (Feb. 10, 2016, 9:15 PM ET), <http://www.usatoday.com/story/news/2016/02/10/birth-defects-linked-zika-may-more-serious-than-they-appear/80177552/> [https://perma.cc/23KK-BJKV].

²² *Facts about Microcephaly*, CTRS. FOR DISEASE CONTROL & PREVENTION (Nov. 21, 2017), <https://www.cdc.gov/ncbddd/birthdefects/microcephaly.html> [https://perma.cc/EJP4-99A3].

concern and investigation, the condition itself is not a death sentence, as some headlines suggested.²³

The tenor of the discourse about Zika made it clear that, in the opinion of many, babies with microcephaly would be better off unborn. Evidence of such birth defects in El Salvador prompted its Deputy Health Minister to request that women stop getting pregnant for two years.²⁴ Health officials in other affected countries, such as Colombia and Jamaica, followed suit with similar advice for women to delay pregnancy for up to a year.²⁵ The implicit messages of these public health advisories is that women in these countries actually have the resources to avoid pregnancy²⁶ and that babies with microcephaly should not be born.²⁷

As of October 2018, the United States has had both travel-related Zika cases and locally acquired Zika cases in Puerto Rico, Florida, Texas, and several other states.²⁸ As a result, the CDC and local health departments played a key role in advising physicians about how to care for patients with Zika, particularly women of reproductive age.²⁹ Because physicians had not seen cases of Zika before, the role of public health guidance was particularly important.³⁰

A. Responses to Zika

When examining Zika as a case study, it is helpful to examine the response in the countries where it first became a crisis, as well as examining the international and U.S. response to the disease. In Latin American countries, Zika prevention was and

²³ *Id.*

²⁴ Nina Liss-Schultz, *Pregnant, Sick with Zika—and Prohibited from Getting an Abortion*, MOTHER JONES, (Jan. 29, 2016, 11:00 AM), <http://www.motherjones.com/politics/2016/01/latin-america-zika-virus-women-pregnancy-abortion> [https://perma.cc/BPT9-9TTY].

²⁵ *Id.*

²⁶ In reality, women in many of these countries do not have such autonomy, due to social structures, religious beliefs, and the legal system. Further, access to contraception is very limited in most of these Zika stricken areas. Additionally, if a woman finds out she is infected with Zika during pregnancy, she does not have abortion as an option in these countries. El Salvador, in fact, has one of the most stringent anti-abortion laws in the world and a high level of sexual violence against women. Yet, public health officials seem to suggest that women have the power to control their reproduction. See Alyson Zureick, Amber Khan, Angeline Chen, & Astrid Reyes, *Physicians' Challenges Under El Salvador's Criminal Abortion Prohibition*, 143 INT. J. GYNECOL. OBSTET., 121, 121–26 (2018).

²⁷ Liss-Shultz, *supra* note 24.

²⁸ 2017 Case Counts in the US, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 2, 2018), <https://www.cdc.gov/zika/reporting/2017-case-counts.html> [https://perma.cc/X5JW-QRYT].

²⁹ See *Zika Travel Information*, *supra* note 16.

³⁰ Beth P. Bell et al., *Preventing Zika Virus Infections in Pregnant Women: An Urgent Public Health Priority*, 106 AM. J. PUB. HEALTH 589, 589–90 (2016).

remains a challenge due to beliefs about contraception and abortion, the costs of such options, and problems of infrastructure.³¹ When facing a mosquito-borne ailment such as Zika, simple measures, such as screens and air conditioning, were the most obvious preventative measures, yet they were unavailable in many urban centers.³² Thus, somewhat surprisingly, when the Zika crisis hit, these impoverished countries' warnings shifted from these preventative measures to placing the burden on women, instructing them to practice safe sex or even to postpone their pregnancies.³³ The following sections outline some of the nongovernmental and governmental responses to the virus to provide a background as to why physician prenatal counseling is so important in this context.

1. WHO Response

There was a multi-prong government response to Zika.³⁴ First, health advisories from countries in Central and South America focused on reducing mosquitos and mosquito contact.³⁵ Additionally, these advisories recommended that pregnant women postpone travel to Zika-affected areas.³⁶ "The WHO declared Zika a global public health emergency on Feb. 1, [2016]," which is significant, as the WHO has only done this three other times in its history.³⁷ The other three times that the WHO declared a "Public Health Emergency of International Concern (PHEIC, pronounced 'fake'). . . . were for swine flu (H1N1) in 2009 and [for both] polio and Ebola in 2014."³⁸

³¹ Anthony S. Fauci & David M. Morens, *Zika Virus in the Americas—Yet Another Arbovirus Threat*, 374 *NEW ENG. J. MED.* 601, 601–04 (2016), <http://www.nejm.org/doi/full/10.1056/NEJMp1600297> [<https://perma.cc/9QFL-LVC3>]; Jude Webber, *Zika Virus: Catholic Group Urges Pope to Allow Contraception*, *FIN. TIMES* (Feb. 11, 2016), <http://www.ft.com/cms/s/0/a02f26d8-d092-11e5-986a-62c79fcbcead.html#axzz40rPHAhkb> [<https://perma.cc/5ZUB-PBFH>].

³² Fauci & Morens, *supra* note 31, at 603.

³³ Webber, *supra* note 31.

³⁴ *Responding to Zika: Ethical Challenges of Zoonotic Diseases*, HASTINGS CTR. (Jan. 29, 2016), <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=7740&blogid=140> [<https://perma.cc/K7HX-5QFD>].

³⁵ *See id.*

³⁶ *Id.*

³⁷ Sewell Chan, *Zika Virus Test is 'Weeks, Not Years' Away, W.H.O. Says*, *N.Y. TIMES* (Feb. 12, 2016), <http://www.nytimes.com/2016/02/13/science/zika-virus-test-vaccine-who.html> [<https://perma.cc/4SWV-QURV>]. The global public health emergency declaration ended November 18, 2017. McNeil, *supra* note 21.

³⁸ Mara Pillinger, *WHO Declared a Public Health Emergency About Zika's Effects. Here Are Three Takeaways*, *WASH. POST* (Feb. 2, 2016), https://www.washingtonpost.com/news/monkey-cage/wp/2016/02/02/who-declared-a-public-health-emergency-about-zikas-effects-here-are-three-takeaways/?noredirect=on&utm_term=.041e352e90ee [<https://perma.cc/3TA9-7CRN>].

The most surprising part of WHO's approach was its focus on pregnancy and abortion. The standard advice was that, in order to protect against Zika, women of childbearing age should use mosquito control measures and safe sex techniques.³⁹ The WHO did not issue travel restrictions, but advised women to assess their own comfort with the risk of travel and to seek medical advice if they do indeed travel to Zika-affected areas.⁴⁰ Additionally, the WHO noted that pregnancy was "a personal decision" that women should make on an informed basis, taking into account the kind and quality of health care services available in their own country.⁴¹

For pregnant women who may have been exposed to Zika, the WHO guidance explained that "[e]arly ultrasound does not reliably predict microcephaly."⁴² Additionally, the WHO recommended that those who wished to terminate their pregnancies due to fears of microcephaly "should have access to safe abortion services to the full extent of the law."⁴³ Due to the abortion restrictions in many countries where Zika was present during the 2016–2017 outbreak, there were often no legal abortion services available.⁴⁴

2. U.S. Government Response

The U.S. government elevated its response to Zika between 2016 and 2017. In early January 2016, the CDC activated emergency operations to respond to Zika in North and South America and reports of increased birth defects.⁴⁵ President Obama also approved funding for research for a Zika vaccine.⁴⁶ Billions of dollars of emergency aid were authorized for Zika response.⁴⁷ Although the CDC stopped its emergency response in 2017, CDC Zika experts continue to do work and research on Zika virus.⁴⁸

³⁹ Stephanie Nebehay, *WHO Urges Precautions in Zika Areas but Reassures Most Births Normal*, REUTERS (Feb. 10, 2016, 12:20 PM ET), <http://www.reuters.com/article/us-health-zika-who/who-urges-precautions-in-zika-areas-but-reassures-most-births-normal-idUSKCN0VJ21I> [<https://perma.cc/A8UW-NRW7>].

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ Jennifer Swann, *Here's the Problem with Telling Women in El Salvador Not to Get Pregnant*, TAKE PART, (Jan. 28, 2016), <http://www.takepart.com/article/2016/01/28/zika-el-salvador-pregnant> [<https://perma.cc/5PEW-GC77>] ("This is another example in which women's bodies become the place of control instead of directing the public crisis, which is this illness We just turn and say, 'Ladies, don't have babies.'").

⁴⁵ *What CDC is Doing*, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 10, 2017), <https://www.cdc.gov/zika/about/whatcdcisdoing.html> [<https://perma.cc/Q6VV-K57L>].

⁴⁶ *Id.*

⁴⁷ *Id.*

⁴⁸ *Id.*

In the aftermath of the Zika epidemic, the government responses of the United States and Latin American countries were highly criticized. Lawrence O. Gostin, director of the O'Neill Institute for National and Global Health Law at Georgetown University, criticized the lack of coordinated help to Latin American countries from the United States.⁴⁹ Such help aided in stopping the Ebola epidemic, but was not forthcoming in the case of Zika.⁵⁰ Politics got in the way of passing the Zika-funding bill, with Congress delaying the bill for months.⁵¹ Cities also fell short in controlling the number of mosquitos, with women in the poorest areas left completely unprotected.⁵² Also, although tourists were often warned of Zika risk, residents were not, and often these women were the ones most affected.⁵³ Finally, many cities focused only on the spread of Zika via mosquitos, mentioning nothing about the fact that sex transmission of the virus is also possible.⁵⁴ Although these are legitimate critiques, the reality is that advising women to delay pregnancy without access to contraception is meaningless. The next section describes these challenges.

B. *Zika and Obstacles for Women*

1. Obstacles to Abortion and Contraception

The initial Zika epidemic produced difficulties for public health officials who were aiming to prevent and reduce harm caused by the virus. Latin American women, the group initially most affected by the Zika virus, lacked access to contraceptives and strict abortion laws.⁵⁵ Thus, the WHO advice was meaningless in many respects, as women who sought to get birth control would have difficulty getting it due to limited supplies of birth control pills and intrauterine devices.⁵⁶ Additionally, in these countries, men are often the ones who decide whether to use birth control and limit family size, rather than women.⁵⁷

More than access to health care, the law is the most significant limit to a female's reproductive health choices in

⁴⁹ McNeil, *supra* note 21.

⁵⁰ *Id.*

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ Liess-Schultz, *supra* note 24.

⁵⁶ Liz Szabo, *Zika Highlights Lack of Access to Contraception, Abortion in Latin America*, USA TODAY (Feb. 2, 2016, 6:48 PM ET), <http://www.usatoday.com/story/news/2016/02/02/zika-highlights-lack-access-contraception-abortion-latin-america/79640840/> [<https://perma.cc/A6VK-ZNDX>].

⁵⁷ *Id.*

Central and South American since abortion is a criminal offense in many Latin American and Caribbean states.⁵⁸ Because of their participation in the American Convention on Human Rights, some Latin American and Caribbean countries are required to allow abortion in the case of a severe or terminal disability.⁵⁹ However, in some of the countries where Zika was rampant—like El Salvador, Nicaragua, Chile, and the Dominican Republic—abortion was illegal with no exceptions for fetal anomalies.⁶⁰

These strict abortion laws raised an issue concerning reproductive justice in light of the Zika outbreak.⁶¹ The WHO and CDC, in addition to the governments of the countries mentioned above, recommended that women should avoid pregnancy.⁶² Such advice is hardly workable if contraception is difficult to obtain. Some women's groups seized on the Zika crisis to expand the right to abortion in certain countries. For example, the vice chair of the International Women's Health Coalition stated that "[t]he rise of microcephaly represents an important opportunity to expand women's rights."⁶³ This framing is similar in form to the framing used by pro-choice activists in the United States in the 1960s who were able to expand abortion access due to the fears of rubella-related anomalies.⁶⁴ As discussed later in this article, this tie is problematic in terms of devaluing the lives and existence of those living with disabilities.⁶⁵ The balancing act required to value a woman's need to control her own body and choices regarding her body, including the right to have an abortion, and also value those who are living with disabilities, is a tough one. However, it is one that is necessary to achieve so that the interests of persons with disabilities, another important group, are not subordinated or set aside in the name of women's rights.

Although abortion is illegal in many Latin American countries, use of medication to self-manage abortion is a widely

⁵⁸ Ligia M. De Jesus, *Abortion in Latin America and the Caribbean: A Comparative Study of Domestic Laws and Relevant Jurisprudence Following the Adoption of the American Convention on Human Rights*, 20 ILSA J. INT'L & COMP. L. 1, 3–4 (2013).

⁵⁹ *Id.* at 23, 46.

⁶⁰ Liess-Schultz, *supra* note 24.

⁶¹ *Responding to Zika: Ethical Challenges of Zoonotic Diseases*, *supra* note 34.

⁶² Sarah Zhang, *Zika Virus May Push South America to Loosen Abortion Bans*, WIRED (Jan. 28, 2016, 7:00 AM), <http://www.wired.com/2016/01/abortion-and-zika-south-america/> [<https://perma.cc/T393-3LTQ>].

⁶³ Will Carless, *The Zika Virus Has Reignited Brazil's Abortion Debate*, PUB. RADIO INT'L: GLOBAL POST (Jan. 28, 2016, 3:15 PM UTC), <http://www.globalpost.com/article/6725607/2016/01/27/brazil-zika-abortion> [<https://perma.cc/JR5G-84VH>].

⁶⁴ See generally LESLIE J. REAGAN, DANGEROUS PREGNANCIES: MOTHERS, DISABILITIES, AND ABORTION IN MODERN AMERICA 139–43 (2010) (discussing how activists helped secure abortion rights by capitalizing upon fears of rubella).

⁶⁵ See *infra* notes 174–179 and accompanying text.

used option.⁶⁶ This option allows women to access abortion without the costs of clinical abortion. In many Latin American countries, such as Brazil, abortion is demarcated by inequality.⁶⁷ As an example, often wealthy women in Brazil are able to get around abortion laws by using a private clinic for a safe, illegal abortion.⁶⁸ Poor women do not have these options, especially later in their pregnancies when medication abortion is not available.⁶⁹ Rich women can get around the law, while poor women fear being sent to prison if they end their pregnancy without the benefit of the protections that an attorney or private clinic can allow.⁷⁰ In the case of Zika, this was particularly relevant because microcephaly is not diagnosable in the early stages of pregnancy, when self-managed abortion is an option.⁷¹ Thus, women who were infected with Zika and found out that their fetus was affected with microcephaly, did not have many options.

2. Obstacles to Raising a Child with Zika-Related Disabilities

When the Zika epidemic and its effect on a fetus came to light, many were concerned about how babies affected by Zika-related anomalies would fare in poor countries lacking adequate support and care for those with disabilities.⁷² While not all babies with microcephaly have such serious brain damage, stories of fears about severe deficits in Zika-affected babies flooded the news.⁷³ Quotes like “[i]n my 30 years in pediatric infectious diseases, I have never seen this level of neurologic devastation in newborns,” demonstrated the attitude towards babies with microcephaly.⁷⁴ Given that many of the countries first affected by the Zika virus were predominantly Catholic, Pope Francis even hinted that

⁶⁶ See MICHELLE OBERMAN, *HER BODY, OUR LAWS: ON THE FRONT LINES OF THE ABORTION WAR, FROM EL SALVADOR TO OKLAHOMA* 45 (2018). (exploring what happens when abortion is a crime, revealing the practical challenges raised by a thriving black market in abortion drugs, and the legal challenges to enforcement that accompany these challenges.

⁶⁷ See Carless, *supra* note 63.

⁶⁸ Sophie Davies, *Faced with Strict Laws, Brazilian Women Keep Abortions Secret*, REUTERS, (May 25, 2016, 7:23 AM), <https://www.reuters.com/article/us-abortion-brazil-secrets/faced-with-strict-laws-brazilian-women-keep-abortions-secret-idUSKCN0YG1GP> [<https://perma.cc/LXC7-ZM6L>].

⁶⁹ See Carless, *supra* note 63. Medication abortion, which is cheaper, is only available within the first ten weeks of pregnancy. *Medication Abortion*, KAISER FAMILY FOUND. (June 1, 2018), <https://www.kff.org/womens-health-policy/fact-sheet/medication-abortion/> [<https://perma.cc/2Q8H-46VK>].

⁷⁰ See Carless, *supra* note 63.

⁷¹ *Microcephaly*, STANFORD CHILDREN'S HEALTH <https://www.stanfordchildrens.org/en/topic/default?id=microcephaly-90-P02610> [<https://perma.cc/8FNE-ZUVT>].

⁷² Szabo, *supra* note 21.

⁷³ *Id.*; see also sources cited *supra* note 21.

⁷⁴ Szabo, *supra* note 21.

Catholics who are afraid of contracting Zika virus may decide to use contraception, as this is less egregious than abortion according to Catholic doctrine.⁷⁵ Although these messages were not explicit, the tenor of the dialogue acknowledged the difficulties faced by families raising a child with a disability.

The burden of these difficulties overwhelmingly fell on women, as evidenced by reports that men were abandoning their partners, leaving mothers to raise children with disabilities by themselves.⁷⁶ Raising a child with severe disabilities is life altering, and a single parent needs financial support.⁷⁷ Many women raising a child with disabilities need to leave their jobs and remain at home caregiving full-time.⁷⁸ For those living in poverty, not working is not an option and, sadly, there is little government support.⁷⁹ At the height of the Zika epidemic, Brazil was facing the possibility that many children born with microcephaly (resulting from Zika) would be abandoned to state care by the time they turned one or two, because of the financial and emotional burden of caregiving.⁸⁰ This highlights the need for increased governmental support for children with disabilities. Unfortunately, when there are competing fiscal pressures, this group often gets ignored and sidelined.

C. *Zika and the Abortion/Disability Message*

Both pro-choice and anti-abortion activists and organizations used the Zika crisis as an opportunity to influence abortion and contraception law and policy in the United States and worldwide.⁸¹ The remainder of this article focuses on the United

⁷⁵ Camila Domonoske, *Pope Suggests Contraception Use May Be 'Lesser Evil' for Those Fearing Zika*, NAT'L PUB. RADIO (Feb. 18, 2016, 12:41 PM ET), <http://www.npr.org/sections/thetwo-way/2016/02/18/467220097/pope-suggests-contraception-use-may-be-lesser-evil-for-those-fearing-zika> [https://perma.cc/7QKQ-DPSH]. However, he did not give explicit approval of birth control. Instead, the Pope's approval is implied from his distinction between the use of abortion and the hypothetical use of contraception to respond to Zika.

⁷⁶ See Lulu Garcia-Navarro, *Moms and Infants Are Abandoned in Brazil Amid Surge in Microcephaly*, Nat'l Pub. Radio (Feb. 18, 2016), <http://www.npr.org/sections/goatsandsoda/2016/02/18/467056166/moms-and-infants-are-abandoned-in-brazil-amid-surge-in-microcephaly> [https://perma.cc/L4XB-G78Q].

⁷⁷ A.L. Curran, et al., *Time Costs of Caring for Children with Severe Disabilities Compared with Caring for Children without Disabilities*, 43 DEV. MED. & CHILD NEUROL., 529, 531–32 (2001).

⁷⁸ See *id.* at 531.

⁷⁹ See *id.*

⁸⁰ Garcia-Navarro, *supra* note 76.

⁸¹ See Chloe Angyal, *Zika Virus Threat Puts Abortion Rights and Disability Rights on Collision Course*, HUFFINGTON POST (Feb. 5, 2016, 12:32 PM ET), https://www.huffingtonpost.com/entry/zika-virus-us-abortion-disability_us_56b2601be4b04f9b57d83192 [https://perma.cc/N2V3-E73E]; Jessica Morgan, *The Zika Virus, Disabilities,*

States, but describing the abortion/contraception access issue in Latin American countries provides a background of the epidemic. Given many states' focus on weakening access to abortion,⁸² the uproar over contraceptive access in the Affordable Care Act,⁸³ and the fear that *Roe v. Wade* may be overruled by the conservative majority in the Supreme Court,⁸⁴ the issue is not as different in the United States as it once may have been. In the United States today, there remains robust debate about abortion and contraceptive access. The wide variety of court challenges to the Affordable Care Act's mandate to include contraception in the panoply of essential health services, including the *Burwell v. Hobby Lobby*⁸⁵ and the *Zubik v. Burwell*⁸⁶ cases, demonstrate examples of this.⁸⁷ Additionally, as the Supreme Court balance has further shifted to a majority conservative court, many fear that abortion access in the United States will be limited greatly in the future.⁸⁸

This article uses the Zika case study to critique the narrative that emerged, pitting access to abortion services as a proposed solution to avoiding raising a child with a disability. Access to health care services, including contraception and

and Pro-Choice Activism, URGE: CHOICEWORDS BLOG (Aug. 30, 2016), <http://urge.org/the-zika-virus-disabilities-and-pro-choice-activism/> [<https://perma.cc/XJC8-4ZYS>].

⁸² Elizabeth Nash et al., *State Policy Trends 2018: With Roe v. Wade In Jeopardy, States Continued to Add New Abortion Restrictions*, GUTTMACHER INST. (Dec. 11, 2018), <https://www.guttmacher.org/article/2018/12/state-policy-trends-2018-roe-v-wade-jeopardy-states-continued-add-new-abortion> [<https://perma.cc/PBL8-DXFY>].

⁸³ Ethan Bronner, *A Flood of Suits Fights Coverage of Birth Control*, N.Y. TIMES (Jan. 26, 2013), <https://www.nytimes.com/2013/01/27/health/religious-groups-and-employers-battle-contraception-mandate.html> [<https://perma.cc/UUF2-LFR8>].

⁸⁴ Nash et al., *supra* note 82.

⁸⁵ See *Burwell v. Hobby Lobby Stores, Inc.*, 134 S. Ct. 2751, 2775–79 (2014) (holding that the HHS contraceptive mandate, as applied for for-profit closely held corporations, substantially burdened the exercise of religion).

⁸⁶ See *Zubik v. Burwell*, 136 S. Ct. 1557, 1559–61 (2016) (per curiam) (the plaintiffs argued that the ACA's contraceptive mandate violated RFRA; the Supreme Court did not reach a decision on the merits of the case, and instead remanded the case to the lower courts to determine how to proceed in a way to balance the conflicting interests of the employer and employee in providing coverage under the contraceptive mandate).

⁸⁷ See Josh Blackman, *The Supreme Court's Punt on the Little Sisters of the Poor Cannot Be Returned*, WASH. POST: VOLOKH CONSPIRACY BLOG (Sept. 23, 2016), https://www.washingtonpost.com/news/volokh-conspiracy/wp/2016/09/23/the-supreme-courts-punt-on-the-little-sisters-of-the-poor-cannot-be-returned/?utm_term=.077b92e9213f [<https://perma.cc/T5SN-898B>].

⁸⁸ See Emily Cochrane, *With Kavanaugh on Court, Abortion Rights Groups Sharpen Their Focus on the States*, N.Y. TIMES (Oct. 19, 2018), <https://www.nytimes.com/2018/10/19/us/politics/kavanaugh-abortion-states-rights.html> [<http://perma.cc/6KCZ-NMKZ>]; Sarah McCammon, *With Kavanaugh Confirmed, Both Sides of Abortion Debate Gear Up For Battle*, NAT'L PUB. RADIO (Oct. 10, 2018, 5:00 AM ET), <https://www.npr.org/2018/10/10/656017613/with-kavanaugh-confirmed-both-sides-of-abortion-debate-gear-up-for-battle> [<http://perma.cc/JX57-VMQS>]; Anna North, *If Kavanaugh Is Confirmed, Any of These 13 Cases Could End Roe v. Wade*, VOX (Sept. 7, 2018, 7:00 AM, EDT), <https://www.vox.com/2018/9/7/17818458/brett-kavanaugh-supreme-court-nominee-abortion-confirmation> [<http://perma.cc/KZ7F-NC7G>].

abortion, and support for those with disabilities are not mutually exclusive.⁸⁹ The Zika case study demonstrates the weakness in public health's focus on primary prevention and harm reduction as unrelated tools. Prevention and harm reduction ought to be intertwined.⁹⁰ Here, harm reduction means encouraging contraception, and thereby avoiding abortions.

Even those who are passionate advocates of a right to control one's reproduction can agree that the goal of reducing abortions reduces harm. Contraception and abortion can be seen as prevention under a public health law analysis, but providing health care services and medical coverage for the disabled is also pivotal to harm reduction.⁹¹ If there was enough support for people with disabilities, having a child born with a disability would not be seen as burdensome and tragic.⁹² In the U.S. context, rather than bolstering services for those with disabilities in light of the Zika epidemic, the Affordable Care Act, which helps to ensure health care and related services for those with disabilities, is currently under attack.⁹³ The Zika crisis highlights this tension between reproductive justice and disability rights in terms of reproductive decision making.⁹⁴ The next Part explores these concepts in more detail.

⁸⁹ See Jennifer Wisdom, et al., *Health Disparities Between Women with and without Disabilities: A Review of Research*, 25 SOC. WORK PUB. HEALTH 368, 370 (2010).

⁹⁰ See *Prevention and Transmission*, CTRS. FOR DISEASE CONTROL & PREVENTION (June 20, 2018), <https://www.cdc.gov/zika/prevention/index.html> [<https://perma.cc/D8PK-X8SX>].

⁹¹ See Sabrina Tavernise, *W.H.O. Recommends Contraception in Countries with Zika Virus*, N.Y. TIMES (Feb. 18, 2016), <https://www.nytimes.com/2016/02/19/health/zika-virus-birth-control-contraception-who.html> [<https://perma.cc/KFR9-5CXC>] (the recommendations issued by the WHO that call for widespread use of contraception in countries impacted by Zika assumes that contraception is widely available); *Prevention and Transmission* *supra* note 90; see also Jeffrey F. Peipert et al., *Preventing Unintended Pregnancies By Providing No-Cost Contraception*, 120 OBSTETRICS & GYNECOLOGY 1291, 1296 (2012) (access to contraception reduces the need for abortion).

⁹² See MARYBETH MUSCUMECI, KAISER FAM. FOUND., *ISSUE BRIEF: THE AFFORDABLE CARE ACT'S IMPACT ON MEDICAID ELIGIBILITY, ENROLLMENT, AND BENEFITS FOR PEOPLE WITH DISABILITIES* 2, 5 (2014), <https://www.kff.org/health-reform/issue-brief/the-affordable-care-acts-impact-on-medicaid-eligibility-enrollment-and-benefits-for-people-with-disabilities/> [<https://perma.cc/8QH3-GKVM>] (highlighting the impact of Affordable Care Act on individuals in the U.S. with disabilities and showing the extent to which state adoption of Medicaid expansion affects coverage for people with disabilities).

⁹³ There has been a concerted effort to repeal the Affordable Care Act for many years since its enactment. See Stephanie Armour, *Conservatives Make New Push to Repeal Affordable Care Act*, WALL ST. J., (June 19, 2018, 2:50 PM ET), <https://www.wsj.com/articles/conservatives-make-new-push-to-repeal-affordable-care-act-1529400721> [<https://perma.cc/V3BB-BRQB>] (noting a plan “to deliver on the eight-year GOP promise to end the ACA”); Julie Rovner, *Timeline: Despite GOP's Failure to Repeal Obamacare, the ACA Has Changed*, WASH. POST (Apr. 5, 2018), https://www.washingtonpost.com/national/health-science/timeline-despite-gops-failure-to-repeal-obamacare-the-aca-has-changed/2018/04/05/dba36240-38b1-11e8-af3c-2123715f78df_story.html?utm_term=.46020d86c50a [<https://perma.cc/82MJ-RVMN>] (providing “a timeline of the most consequential events that have shaped the health law” since President Trump's “first day in office”).

⁹⁴ See Angyal, *supra* note 81.

II. REPRODUCTIVE RIGHTS, DISABILITY RIGHTS, AND REPRODUCTIVE JUSTICE: SHIFTING TO AN INTERSECTIONAL FRAMEWORK

The first Part of this article used the Zika case study to show how the need to ensure reproductive health care for women, in the form of abortion and contraception, often unknowingly undermined the needs and interests of those with disabilities. In order to apply theory to this analysis, this Part briefly outlines the reproductive rights, disability rights, and reproductive justice frames. This Part concludes that the reproductive rights and justice movements should more consciously embrace an intersectional perspective in order to include the interests of those with disabilities.

A. *Reproductive Rights*

Traditionally, in the United States, women's rights organizations have focused on a woman's right to have control over her body, either by controlling reproduction through the use of contraception or by deciding whether to terminate a pregnancy. Reproductive freedom requires "a formal recognition that the woman, rather than the state, has the right to make decisions that affect her reproduction."⁹⁵ In addition to freedom from reproductive control, it requires government neutrality.⁹⁶ Finally, and most importantly, it requires affirmative reproductive liberty, which has been described as "a social context that affirmatively supports and enhances human freedom to make reproductive choices."⁹⁷ The reproductive rights movement spurred from the women's right movement with its goals of gender equality, self-determination via reproductive and sexual freedom, "full participation in society, and emancipation from patriarchal control."⁹⁸ The reproductive rights movement focused primarily on the need for "increased access to contraception and abortion."⁹⁹

The reproductive rights movement got its biggest win with the Supreme Court's decision in *Roe v. Wade*. In 1973, the Supreme Court held that the Due Process Clause of the Fourteenth Amendment protected substantive rights such as personal privacy¹⁰⁰ and further that such privacy included the right to choose

⁹⁵ Rachael N. Pine & Sylvia A. Law, *Envisioning A Future for Reproductive Liberty: Strategies for Making the Rights Real*, 27 HARV. C.R.-C.L. L. REV. 407, 414 (1992).

⁹⁶ *See id.*

⁹⁷ *Id.*

⁹⁸ *See* Angela Hooton, *A Broader Vision of the Reproductive Rights Movement: Fusing Mainstream and Latina Feminism*, 13 AM. U. J. GENDER SOC. POLY & L. 59, 61 (2005).

⁹⁹ *Id.*

¹⁰⁰ *Roe v. Wade*, 410 U.S. 113, 152 (1973).

whether or not to continue a pregnancy.¹⁰¹ The *Roe* Court held that this right to choose an abortion was a fundamental right and thus could not be burdened, other than when the burdens on women are narrowly tailored to further a compelling state interest.¹⁰² *Roe* recognized that a state only had a compelling interest in the fetus after viability.¹⁰³ Although *Roe* was a high point for reproductive rights activists, subsequent Supreme Court jurisprudence has narrowed *Roe's* impact considerably.¹⁰⁴ In *Planned Parenthood v. Casey*, the Court balanced a woman's interest in procreative liberty with a state's legitimate interest in potential life.¹⁰⁵ In *Casey*, the Court held that states could regulate abortion at any point prior to viability, as long as the state did not unduly burden a woman's right to choose an abortion.¹⁰⁶ Furthermore, the Court stated that "[a]n undue burden exists . . . if [a regulation's] purpose or effect is to place a substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability."¹⁰⁷ Practically, because states are allowed to determine what an undue burden is, many states have promulgated severe restrictions on abortion access, from parental notification laws, waiting periods, counseling requirements, and requirements for providers.¹⁰⁸ Although ACOG, the national organization of obstetrics and gynecology, readily recognizes abortion and contraception as health care services that should be made available to women,¹⁰⁹ the U.S. Supreme Court has narrowly based the right to abortion on a woman's privacy interest.

In *Whole Woman's Health v. Hellerstedt*,¹¹⁰ a case involving a challenge to two Texas laws, one requiring abortion providers to

¹⁰¹ *Id.* at 153.

¹⁰² *Id.* at 155.

¹⁰³ *Id.* at 159–64.

¹⁰⁴ For example, by upholding parental consent laws and disallowing federal payment for abortion to Medicaid recipients, the Supreme Court has limited abortion access for poor and young women. See Hooton, *supra* note 98, at 64–66.

¹⁰⁵ *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 878 (1992).

¹⁰⁶ *Id.* at 878–79.

¹⁰⁷ *Id.* at 878.

¹⁰⁸ See Hooton, *supra* note 98, at 63–64.

¹⁰⁹ Am. Coll. of Obstetricians & Gynecologists, Comm. on Health Care for Underserved Women, Comm. Op. 613 (2014), <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Increasing-Access-to-Abortion> [<https://perma.cc/73K9-94PX>] (“Safe, legal abortion is a necessary component of women’s health care.”); Am. Coll. of Obstetricians & Gynecologists, Comm. on Health Care for Underserved Women, Comm. Op. 615 (2015), <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Access-to-Contraception> [<https://perma.cc/RV54-5QCB>] <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Access-to-Contraception?%20alse> [<https://perma.cc/CSP3-PULJ>] (“All women should have unhindered and affordable access to all U.S. Food and Drug Administration-approved contraceptives.”).

¹¹⁰ *Whole Woman's Health v. Hellerstedt*, 136 S. Ct. 2292, 2292 (2016).

have admitting privileges at a nearby hospital¹¹¹ and another requiring clinics to fulfill requirements of ambulatory surgical centers,¹¹² the Court applied a stricter version of *Casey*'s undue burden test. In a vote of 5-to-3, the Court struck down both provisions.¹¹³ The Court concluded that *Casey* required courts to balance the benefits and costs of abortion restrictions.¹¹⁴ As the Southern District of Indiana later noted, "nothing in *Roe*, *Casey*, or any other subsequent Supreme Court decisions suggests that a woman's right to choose an abortion prior to viability can be restricted if exercised for a [compelling governmental interest]."¹¹⁵

In the current political environment, and with the progression in the case law since *Roe*, there is a fear that *Roe* will be overturned or even more severely limited.¹¹⁶ Thus, Planned Parenthood and other reproductive rights organizations are mobilizing to defend the right to abortion services.¹¹⁷ In focusing solely on these issues, however, reproductive rights groups often ignored the needs and concerns of minority women and women who may have disabilities or other special needs.¹¹⁸ The reproductive rights movement was created and defined by white women, and African-American women's struggles were often ignored.¹¹⁹ Angela Harris, an esteemed critical race theorist, notes that "race, class, sexual orientation, and other realities of experience" are often not considered in the feminist movement.¹²⁰ The reproductive justice movement developed as a reaction to the mainstream reproductive rights movement.¹²¹

B. Reproductive Justice

The term "reproductive justice" refers to a theory developed by women of color, to reorient the conversation of the reproductive

¹¹¹ TEX. HEALTH & SAFETY CODE ANN. § 171.0031(a)(1) (West 2017); 25 TEX. ADMIN. CODE §§ 139.53(c)-56(a) (2017).

¹¹² TEX. HEALTH & SAFETY CODE ANN. § 245.010(a) (West 2017); 25 TEX. ADMIN. CODE § 139.40 (2018).

¹¹³ *Hellerstedt*, 136 S. Ct. at 2299–2300.

¹¹⁴ *Id.* at 2309–10.

¹¹⁵ *Planned Parenthood of Ind. & Ky., Inc. v. Comm'r, Ind. State Dep't of Health*, 265 F. Supp. 3d 859, 869 (S.D. Ind. 2017)

¹¹⁶ See *supra* note 82–88 and accompanying text.

¹¹⁷ See *supra* note 88 and accompanying text.

¹¹⁸ The sole focus on abortion services has historically ignored these additional groups—for example, see discussion of Rubella *infra* notes 174–179 and accompanying text.

¹¹⁹ Melanie M. Lee, *Defining the Agenda: A New Struggle for African-American Women in the Fight for Reproductive Self-Determination*, 6 WASH. & LEE RACE & ETHNIC ANCESTRY L.J. 87, 95–96 (2000); Hooton, *supra* note 98, at 65.

¹²⁰ Angela P. Harris, *Race and Essentialism in Feminist Legal Theory*, 42 STAN. L. REV. 581, 585 (1990).

¹²¹ See *infra* Section II.B.

rights movement from just abortion and contraception, to other barriers related to reproductive freedom that women of color and poor women face.¹²² The reproductive justice movement moves beyond the traditional white women led reproductive rights movement which focused on choice and the experiences of privileged women.¹²³ Reproductive justice embodies the “complete physical, mental, spiritual, political, social, and economic well-being of women and girls, based on the full achievement and protection of women’s human rights.”¹²⁴

Loretta Ross¹²⁵ explained her intention of shying away from the pro-choice language and instead using the term reproductive justice because minority women represent communities with few real choices.¹²⁶ Reproductive justice integrates the concepts of reproductive rights, social justice, and human rights.¹²⁷ Instead of just focusing on abortion rights, those who support reproductive justice “fight equally for: (1) the right to have a child; (2) the right not to have a child; and (3) the right to parent the children [they] have.”¹²⁸ This is a significant change from the reproductive rights movement, which had mainly focused on securing abortion rights. As a consequence, there is a need for a wider lens that includes allowing women to have support in having children, not just ensuring they have access to needed tools to limit reproduction. Historically, women of color were often victims of forced sterilization.¹²⁹ They were often targeted as unfit mothers and had the state take away their children in cases of drug use during pregnancy.¹³⁰

Thus, reproductive justice expands the lens from just access to contraception and abortion to rights to “comprehensive sex education, [sexually transmitted disease] prevention and care,

¹²² *Reproductive Justice*, SISTER SONG, <http://sistersong.net/reproductive-justice/> [<https://perma.cc/6KWF-KZ8L>].

¹²³ *Id.*

¹²⁴ Loretta Ross, *What is Reproductive Justice?*, in REPRODUCTIVE JUSTICE BRIEFING BOOK: A PRIMER ON REPRODUCTIVE JUSTICE AND SOCIAL CHANGE 4, 4 <https://www.law.berkeley.edu/php-programs/courses/fileDL.php?fID=4051> [<https://perma.cc/LQ4C-QBA6>].

¹²⁵ “Loretta J. Ross is a Visiting Professor of Practice in the School of Social Transformation at Arizona State University,” and is “one of the creators of the term ‘Reproductive Justice’ coined by African American women in 1994.” See *Biography*, LORETTA ROSS, <https://www.lorettaross.com/Biography.html> [<https://perma.cc/F5Y4-EUS9>].

¹²⁶ *What Is Reproductive Justice?*, FORWARD TOGETHER, <http://strongfamiliesmovement.org/what-is-reproductive-justice> [<https://perma.cc/ZZH2-HC3Y>]; *Reproductive Justice*, *supra* note 122.

¹²⁷ See *What Is Reproductive Justice?*, *supra* note 126.

¹²⁸ Ross, *supra* note 124, at 4.

¹²⁹ See Dorothy Roberts, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* 56–57 (Vintage Books 2d ed. 2017).

¹³⁰ See *id.* at 56.

alternative birth options, adequate prenatal and pregnancy care, domestic violence assistance, adequate wages to support families, [and] safe homes.”¹³¹ The movement pushes for a society and support that enables these rights.¹³² By moving beyond the traditional pro-choice narrative and into the reality of lived experiences within the women’s communities, the reproductive justice movement focuses on the inequality among groups of women that inhibits access to these rights for some more than others.¹³³ A discussion of the unique problems that women of color and poor women face in raising children and accessing health care is part of the reproductive justice frame. Just as these populations face additional difficulties, so do populations of people with disabilities.

Reproductive justice focuses on the social context in which reproduction occurs—an environment of racial and social inequity and “reproductive oppression.”¹³⁴ Reproductive justice attempts to transcend issues of “individual rights, choice, and personal health to address more systemic and institutional impediments to realizing full reproductive and sexual freedom.”¹³⁵ This has included a focus on governmental duties and the laws that create and worsen inequalities on the local, state, national, and international level.¹³⁶ Reproductive justice attempts to include the concerns of “gay, lesbian, bisexual and transgender people.”¹³⁷ Individuals with disabilities fit squarely into the marginalized populations reproductive justice aims to speak for, and this theoretical framework should therefore be expanded to protect this population.¹³⁸

C. Disability Rights

It is important to view this issue from the lens of disability rights. “[T]he disability rights movement started with the observation that people with disabilities share a common experience of systematic exclusion . . . [T]he very notion of

¹³¹ *Reproductive Justice*, *supra* note 122.

¹³² Ross, *supra* note 124, at 4.

¹³³ *See id.*

¹³⁴ *A Vulnerability and the Human Condition Initiative and Northeastern University School of Law Workshop*, NE. U. SCH. OF L., <http://www.northeastern.edu/law/academics/conferences/reproductive-justice/index.html> [<https://perma.cc/6WK4-CX7P>]; *see also* Rachel Rebouché, *Reproducing Rights: The Intersection of Reproductive Justice and Human Rights*, 7 U.C. IRVINE L. REV. 579, 593 (2017).

¹³⁵ *A Vulnerability and the Human Condition Initiative and Northeastern University School of Law Workshop*, *supra* note 134.

¹³⁶ *Id.*

¹³⁷ *Id.*

¹³⁸ Jessica Boyer, *A Time to Lead: A Roadmap for Progress on Sexual and Reproductive Health and Rights Worldwide*, 21 GUTTMACHER POL’Y REV. 35, 38 (2018).

‘disability’ depends crucially on the social practices that create that shared experience.”¹³⁹ One of the key tenets of the disability rights movement is that “‘disability’ is not an inherent trait of the ‘disabled’ person.”¹⁴⁰ Instead, “disability” is more a result of circumstance and societal expectation than a conscious choice.¹⁴¹ Traditionally, the disability rights movement advocated for civil rights legislation to address this lack of access for people with disabilities.¹⁴² The movement sought to reframe the picture of disability from a “‘personal tragedy’—‘some terrible chance event which occurs at random to unfortunate individuals’”—to a condition that requires accommodation rather than pity.¹⁴³ This narrative of a tragedy was very much present in the framing of the Zika epidemic. The news stories previously discussed portray it as a catastrophe to have a child born with microcephaly.¹⁴⁴ It is important to note commonalities and areas of overlap between disability rights and reproductive rights. Although reproductive justice uses a form of an intersectionality frame, it is necessary that a reproductive justice analysis take careful account of disability along with race and class in analyzing issues around Zika and other prenatal diagnoses.

¹³⁹ Samuel R. Bagenstos, *Subordination, Stigma, and “Disability”*, 86 VA. L. REV. 397, 426 (2000).

¹⁴⁰ *Id.*

¹⁴¹ *Id.* There are several models of disability. The “moral model . . . regards disability as the result of sin,” while the medical model sees “disability as a defect or sickness that must be cured through medical intervention.” Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 J. HEALTH CARE L. & POL’Y 352, 352 (2000). The rehabilitation model envisions “disability as a deficiency that must be fixed by a rehabilitation professional or other helping professional,” and the disability model focuses on the lack of adequate support services for those with disabilities “when compared with society generally, as well as attitudinal, architectural, sensory, cognitive, and economic barriers, and the strong tendency for people to generalize about all persons with disabilities overlooking the large variations within the disability community.” *Id.* at 352–53.

¹⁴² Bagenstos, *supra* note 139, at 426.

¹⁴³ *Id.* at 427 (quoting MICHAEL OLIVER, UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE 32 (1996)). Prior to the rise of the disability rights movement in the 1970s, disability care was just “focused on medical treatment, physical rehabilitation, charity, and public assistance.” *Id.* Thus, the disability rights movement was a direct “reaction to that ‘medical/pathological paradigm’ of disability.” *Id.* One of the goals of the disability rights movement was moving away from seeing disability “as an inherent personal characteristic that should ideally be fixed.” *Id.*

¹⁴⁴ See *supra* Section I.B.2.

D. *Finding Common Ground—the Need for Intersectionality*

Intersectionality can be used as a tool to understand the relationship between various identity-based groups.¹⁴⁵ An intersectional analysis can help “build...alliances between movements to make them more effective at organizing for social change.”¹⁴⁶ Intersectionality can be used to reveal weaknesses with leading “legal” methodologies, characterizing “discrimination” by one individual factor and consequently disregarding those individuals affected by multiple injustices.¹⁴⁷ Intersectionality has several noteworthy approaches “for feminist theorizing” and “political activism;” however, one of the most significant methods is utilizing “active engagement” amongst individuals, thereby allowing them to pursue and form “commonalities” between them.¹⁴⁸ Finding these common experiences show ways that diverse groups are able to come together and connect.¹⁴⁹ Using intersectionality helps to create alliances in order to drive “social change.”¹⁵⁰

The disability rights movement often highlights the stigma of disability and the need for economic support for individuals and their families, while the reproductive justice approach focuses on a broader debate—advocating for women to have the resources “to make the best decisions for themselves and their families” which includes “ensuring that women have the most accurate and comprehensive information possible, including realistic perspectives from individuals with the disability in question.”¹⁵¹ Reproductive justice groups are not necessarily anti-disability, but they are concerned about the challenges that face these women when deciding to terminate a pregnancy.¹⁵²

¹⁴⁵ Sumi Cho, Kimberlé Williams Crenshaw & Leslie McCall, *Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis*, 38 SIGNS: J. WOMEN CULTURE & SOC'Y 785, 785 (2013).

¹⁴⁶ Dorothy Roberts & Sujatha Jesudason, *Movement Intersectionality: The Case of Race, Gender, Disability, and Genetic Technologies*, 10 DU BOIS REV.: SOC. SCI. RES. RACE 313, 313 (2013).

¹⁴⁷ Kimberle Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. LEGAL F. 139, 140 (1989).

¹⁴⁸ Roberts & Jesudason, *supra* note 146, at 316.

¹⁴⁹ *See id.* at 315.

¹⁵⁰ *Id.* at 314–15.

¹⁵¹ Sujatha Jesudason & Julia Epstein, *The Paradox of Disability in Abortion Debates: Bringing the Pro-Choice and Disability Rights Communities Together*, 84 CONTRACEPTION 541, 542 (2011).

¹⁵² *Id.*

Dorothy Roberts, a law and sociology professor and an internationally renowned reproductive justice expert,¹⁵³ and Sujatha Jesudason, an activist who works with reproductive justice and disability rights issues,¹⁵⁴ argue that both the reproductive justice movement and the disability rights movement can learn from each other.¹⁵⁵ “The disability rights approach highlights the . . . stigma” of the label “disability” itself, and positions it outside the person who is subject to such a label.¹⁵⁶ A reproductive justice approach advocates for a supportive government that allows all women, regardless of race, ableism, or class, to lead meaningful lives, which includes making decisions with accurate information.¹⁵⁷ For example, in a case where a woman’s child has been diagnosed before birth with a disability, she requires timely, accurate information, support, and access to services.¹⁵⁸ Similarly, intersectionality can be used to address the problems identified in the Zika case study, and better guidance can and should be implemented in the case of future outbreaks. This article suggests how physician guidance can incorporate concerns of the disability rights and reproductive justice movements.

The realms of race, sex, and ability or disability interact in many ways when it comes to policy.¹⁵⁹ Policies regarding prenatal screening can be seen as reinforcing the idea that there is a “biological explanation[] for social problems.”¹⁶⁰ The “[a]dvances in reproductive-assisting technologies” in general now allow methods to “de-select for disability.”¹⁶¹ Treating disability as a medical problem, instead of a social problem that requires accommodation, makes it seem like the person with disabilities is the crux of the problem.¹⁶² However, the disability rights movement highlights that the problem that needs solving is the failure of society to provide social and physical support for the person’s condition.¹⁶³ Instead of placing the focus on lessening stigma, providing financial and social support, and making the physical environment more accessible, solving the genetic problem by aborting a fetus due

¹⁵³ *Penn Law Faculty: Dorothy E. Roberts*, UNIV. OF PA. L. SCH., <https://www.law.upenn.edu/cf/faculty/roberts1/> [<https://perma.cc/T4UX-3WR9>].

¹⁵⁴ *Sujatha Jesudason—Professor of Professional Practice in Management—Public Engagement*, NEW SCH., <https://www.newschool.edu/public-engagement/faculty-list/?id=4e6a-5978-4e54-6b7a> [<https://perma.cc/3DV4-PEVJ>].

¹⁵⁵ Roberts & Jesudason, *supra* note 146, at 314.

¹⁵⁶ Jesudason & Epstein, *supra* note 151, at 542.

¹⁵⁷ *Id.*

¹⁵⁸ *Id.*

¹⁵⁹ Roberts & Jesudason, *supra* note 146, at 317.

¹⁶⁰ *Id.*

¹⁶¹ *Id.*

¹⁶² *Id.* at 318.

¹⁶³ *Id.*

to disability shortchanges the lives of people with disabilities.¹⁶⁴ An intersectional approach allows a focus on both reproductive options and sources of support.

Generations Ahead, an organization that had sought to protect human rights in the use of genetic technologies, has used this intersectionality approach to encourage dialogue “between reproductive justice and disability rights leaders.”¹⁶⁵ Generations Ahead hosted representatives from both groups to discuss how they approached genetic testing and abortion.¹⁶⁶ “Instead of [clashing] over whether to regulate abortion and prenatal screening to prevent the de-selection of people with disabilities or allow unfettered reproductive freedom that could lead to the eugenic elimination of disability,” by using the intersectionality framework, the two groups were ultimately able to agree on a model for how to deal with genetic technologies, taking into account some long-term and wide-ranging policies to help bring about structural changes that would lead to greater social equality for those with disabilities.¹⁶⁷ The intersectionality approach allowed two opposing groups to identify shared values and make each side more inclusive while both affirming their individual goals of women’s autonomy and value for the lives of individuals with disabilities.¹⁶⁸ Because of this process, these two movements went on to work together on several collaborative projects that allowed them to advocate for abortion access while respecting those with disabilities.¹⁶⁹ One of these projects was to lobby to increase funding for the Prenatally and Postnatally Diagnosed Conditions Awareness, which is one of the solutions this article advocates for in Part IV.¹⁷⁰

E. Tensions Between Reproductive Rights and Disability Rights in Activism and Jurisprudence

This section discusses the tensions that have long existed between reproductive rights and disability rights in the United States, particularly as a part of access to abortion services

¹⁶⁴ *Id.*

¹⁶⁵ *Id.* at 321. Sadly, in January 2012, Generations Ahead “closed as an organization.” GENERATIONS AHEAD, www.generations-ahead.org [https://perma.cc/VFY3-FNUX].

¹⁶⁶ Roberts & Jesudason, *supra* note 146, at 321.

¹⁶⁷ *Id.* at 322 (citing GENERATIONS AHEAD, BRIDGING THE DIVIDE: DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS AND JUSTICE ADVOCATES DISCUSSING GENETIC TECHNOLOGIES 2 (2009), http://www.generations-ahead.org/files-for-download/articles/GenAheadReport_BridgingTheDivide.pdf [https://perma.cc/6Y78-M2ZF]).

¹⁶⁸ *Id.* at 322–23.

¹⁶⁹ *Id.* at 323–24.

¹⁷⁰ *Id.* at 323–24; *see also infra* Section IV.A.

advocacy. Although continually challenged, the right to an abortion is well established in U.S. jurisprudence.¹⁷¹ Additionally, procreative liberty, the “negative right against state interference with choices to procreate or to avoid procreation,”¹⁷² has long been recognized as the backbone of reproductive medical decision making. John Robertson argued that “[t]o deny procreative choice is to deny or impose a crucial self-defining experience, thus denying persons respect and dignity at the most basic level.”¹⁷³ This article contends that this includes meaningful support of procreative choice both to have a child with a disability as well as affirmative right to avoid procreation.

1. Using Disability as a Tool in Abortion Activism

Both pro-choice and anti-abortion groups use disability as a tool to further their goals. A big part of the history of the right to abortion in the United States is based in negative attitudes towards disability. During the 1960s, rubella was a threat to pregnant women wishing to carry to term and birth a healthy baby.¹⁷⁴ Married, middle-class, white women teamed up with their husbands, politicians, lawyers and others to fight for the right to abortion, because bearing a child with disabilities presented many challenges to the family and to society.¹⁷⁵ Even pastors and rabbis created the Clergy Consultation Service on Abortion to help poor women with unplanned pregnancies and help find them safe illegal abortion.¹⁷⁶ Women fought for the right to abortion using the argument that they should be the ones with the moral authority and responsibility to consider the dangers and difficulties of their situation and to make the final decision regarding their pregnancy.¹⁷⁷ These women “insisted upon the right to honest information and the right to safe, legal abortion procedures.”¹⁷⁸ Additionally, as ultrasound and prenatal testing made it more “possible to identify disabilities before birth, pro-choice physicians, lawyers, and activists made disability-based justifications a centerpiece of the demand for the reform of abortion laws.”¹⁷⁹

¹⁷¹ See *supra* Section II.A.

¹⁷² JOHN A. ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 23 (1994).

¹⁷³ *Id.* at 4.

¹⁷⁴ LESLIE J. REAGAN, DANGEROUS PREGNANCIES: MOTHERS, DISABILITIES, AND ABORTION IN MODERN AMERICA 1 (2010).

¹⁷⁵ *Id.* at 6, 139–79, 223.

¹⁷⁶ *Id.* at 157.

¹⁷⁷ *Id.* at 224.

¹⁷⁸ *Id.*

¹⁷⁹ Mary Ziegler, *The Disability Politics of Abortion*, 2017 UTAH L. REV. 587, 590 (2017).

A common critique of anti-abortion groups is that they seem more concerned about people with disabilities when they are fetuses than as babies.¹⁸⁰ It is difficult to find any examples of anti-abortion groups who help those with disabilities. This focus seems to stop at birth, and there seems to be no effort to provide tangible support to assist individuals with disabilities of their families.¹⁸¹ As one scholar stated, “pro-life activists have politicized the experiences of disabled individuals to build momentum for abortion restrictions by seeking to proclaim ‘the value of all life, including individuals with and without disabilities.’”¹⁸² For example, North Dakota¹⁸³ and Indiana¹⁸⁴ passed legislation to limit access to so-called disability selective abortion services, and both laws were deemed to impose an undue burden on a woman’s right to abortion. In the most recent example, the Indiana legislature passed the Sex Selective and Disability Abortion Ban.¹⁸⁵ The law required that providers inform their patients “[t]hat Indiana does not allow a fetus to be aborted solely because of the fetus’s race, color, national origin, ancestry, sex, or diagnosis or potential diagnosis of the fetus having Down syndrome or any other disability.”¹⁸⁶ In *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r, Indiana State Dep’t of Health*,¹⁸⁷ the United States District Court for the Southern District of Indiana struck down this ban due to *Casey*’s holding that “[i]t is a constitutional liberty of the woman to have some freedom to terminate her pregnancy.”¹⁸⁸ The Indiana attorney general’s

¹⁸⁰ Warren J. Blumenfeld, *The Hypocrisy of ‘Pro-Life’ and the GOP*, HUFFINGTON POST (May 19, 2016, 10:08 AM ET), https://www.huffingtonpost.com/warren-j-blumenfeld/the-hypocrisy-of-prolife-and-the-gop_b_7294178.html [https://perma.cc/J6X2-QCDK]; Kristina Chew, *Would You Abort a Disabled Child?*, GUARDIAN (Apr. 22, 2013, 7:00 AM EDT), <https://www.theguardian.com/commentisfree/2013/apr/22/abort-down-syndrome-child-society-shares-blame> [https://perma.cc/H38E-XPJ8]; Ivanova Smith, *Republicans Who Claim to Be Pro-Life but Support Gutting Medicaid Are Hypocrites*, MIC DAILY (July 27, 2017), <https://mic.com/articles/182969/republicans-who-claim-to-be-pro-life-but-support-gutting-medicaid-are-hypocrites#.k6SytIzVm> [https://perma.cc/AC57-JP69].

¹⁸¹ Stefanija Giric, *Strange Bedfellows: Anti-Abortion and Disability Rights Advocacy*, 3 J.L. & BIOSCIENCES 736, 741 (2016).

¹⁸² *Id.* (quoting Jesudason & Epstein, *supra* note 151, at 541–43).

¹⁸³ N.D. CENT. CODE ANN. § 14-02.1-04.1 (West 2017). “In 2013, North Dakota enacted House Bill 1305, which prohibits any provider from performing an abortion when she knows that the procedure is sought solely for purposes of sex selection or because the fetus has been diagnosed with a ‘genetic abnormality or a potential for a genetic abnormality.’” Ziegler, *supra* note 179, at 614 (quoting N.D. CENT. CODE ANN. § 14-02.1-04.1 (West 2017)).

¹⁸⁴ IND. CODE §§ 16-34-4-6–16-34-4-7 (2017).

¹⁸⁵ IND. CODE § 16-34-4 (2017).

¹⁸⁶ IND. CODE § 16–34–2–1.1(a)(1)(K) (2017).

¹⁸⁷ *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r, Ind. State Dep’t of Health*, 265 F. Supp. 3d 859, 859 (S.D. Ind. 2017) (quoting *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 846 (1992)).

¹⁸⁸ *Id.* at 865. The court noted that this liberty interest is found “in the right to privacy rooted in ‘the Fourteenth Amendment’s concept of personal liberty’” expounded by *Roe v. Wade*. *Id.* (quoting *Roe v. Wade*, 410 U.S. 113, 153 (1973)). Citing *Casey*,

office filed a petition for writ of certiorari with the U.S. Supreme Court, requesting that the high court review and reverse a United States Court of Appeals for the Seventh Circuit decision that found certain provisions of an Indiana abortion law unconstitutional.¹⁸⁹

2. The Need to Move Toward Reproductive Justice

While Supreme Court jurisprudence on women's health has been focused on just abortion, feminists and women's health advocates find themselves trying to get past the abortion-focus of the pro-choice movement to address a wider range of issues affecting women's well-being.¹⁹⁰ Planned Parenthood and the National Organization of Women (NOW) currently focus on issues regarding health care coverage, contraceptive access, in addition to abortion services.¹⁹¹ NOW made an effort to include intersectional viewpoints in its national platform, noting that it "provides a forum for women of color to support and organize for social, political, economic and reproductive justice."¹⁹² The focus of the reproductive justice movement discussed in Part I seems to be bearing fruit on the activism front; however, the movement is hampered by the Supreme Court.

Supreme Court jurisprudence has framed abortion "on a commitment to negative rights and libertarian premises."¹⁹³ This is a legal fiction that constrains how the state provides care. Because it is difficult and impractical to articulate advice based upon a privacy rationale, such negative framing does not help a woman like

Stenberg v. Carhart, and *Gonzales v. Carhart*, the district court stated that a "woman's right to choose to terminate a pregnancy pre-viability is categorical: 'a State may not prohibit any woman from making the ultimate decision to terminate her pregnancy before viability.'" *Id.* at 866 (citing *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 879 (1992).; *Stenberg v. Carhart*, 530 U.S. 914, 920 (2000); *Gonzales v. Carhart*, 550 U.S. 124, 146 (2007)). The district court noted, "nothing in *Roe*, *Casey*, or any other subsequent Supreme Court decisions suggests that a woman's right to choose an abortion prior to viability can be restricted if exercised for a particular reason determined by the State. The right to a pre-viability abortion is categorical." *Id.* at 869.

¹⁸⁹ See Petition for Writ of Certiorari at 1, *Box v. Planned Parenthood of Ind. & Ky., Inc.*, 888 F.3d 300 (7th Cir. 2018), *petition for cert. filed*, 2018 WL 3655854 (U.S. Oct. 12, 2018) (No. 18-483); Olivia Covington, *Advocates: Abortion Ruling Continues Unconstitutional Trend*, IND. LAW. (July 26, 2018), <https://www.theindianalawyer.com/articles/47684-advocates-abortion-ruling-continues-unconstitutional-trend> [<https://perma.cc/3NSE-VJYV>].

¹⁹⁰ See Ziegler, *supra* note 179, at 623-24; see Jackie Calmes, *Activists Shun Pro-Choice' to Expand Message*, N.Y. TIMES (July 28, 2014), <http://www.nytimes.com/2014/07/29/us/politics/advocates-shun-pro-choice-to-expand-message.html> [<https://perma.cc/8PGB-X3EN>].

¹⁹¹ Cecile Richards, *We're Fighting for Access, Not Choice*, HUFFINGTON POST (Sept. 29, 2014, 7:52 PM ET), http://www.huffingtonpost.com/dawn-laguens/were-fighting-for-access_b_5635999.html [<https://perma.cc/23VQ-QTDN>].

¹⁹² See Ziegler, *supra* note 179, at 624 n.252 (quoting 2004 NOW National Conference Resolutions, NAT'L NOW TIMES, Oct. 1, 2004, at 13).

¹⁹³ Robin West, *From Choice to Reproductive Justice: De-Constitutionalizing Abortion Rights*, 118 YALE L.J. 1394, 1431 (2009).

Jennelle from the introductory hypothetical.¹⁹⁴ How does a privacy right help someone who may be raising a child with expensive health care and childrearing costs? Robin West, Frederick Haas Professor of Law and Associate Dean of Research and Academic Programs at Georgetown University Law Center, eloquently states:

Women need legal abortion not to ward off undue state interference, but in order to live better and more integrated lives in their families and workplaces both. And to live those better and more integrated lives, they require both reproductive choice and better support for their caregiving obligations, as do the men with whom they might partner. Viewed as pragmatic needs for well-led lives, rather than principled demands for rights, better supports for childcare and legal abortion are both components of an as yet unrealized reproductive justice. Only when elevated to the level of constitutional and timeless principle does the argument for one component seem to undercut the case for the other.¹⁹⁵

West argues that reproductive justice in women's lives should allow rights-based claims, but that the movement should use its legal resources to demand those claims in the "state and federal legislative arenas."¹⁹⁶ She argues that by framing abortion as just one of the many options available, "pro-choice advocates might find common cause with pro-life movements that responsibly seek greater justice for pregnant women who choose to carry their pregnancies to term, working families, and struggling mothers."¹⁹⁷ West's reasoning applies to the disability rights advocates as well.¹⁹⁸ Lowering the cost and difficulty of raising a child with a disability is a worthy goal that would also likely reduce the number of abortions being sought. Thus, disability rights and reproductive justice advocates could find

¹⁹⁴ See *supra* note 1.

¹⁹⁵ West, *supra* note 193, at 1431.

¹⁹⁶ *Id.* at 1396–97. To an extent, the Affordable Care Act went far in helping ensure women's health was protected. The essential health benefits all health plans had to include incorporated maternity care and contraceptive coverage. Abortion and assisted reproduction are two types of health care services that can also be crucial to a woman's well-being. However, for political and financial reasons, neither was included as an essential health benefit. Given the controversy and surrounding litigation against including contraception, such an omission was likely pragmatic. See 42 U.S.C. § 18022(b)(1)(D) (2012) (listing "maternity and newborn care" as an essential health benefit); *id.* § 18022(b)(1)(I) (listing preventative and wellness services as an essential health benefit); see also Alicia Gallegos, *Trump Administration Rule Erodes ACA Contraceptive Mandate*, OB.GYN. NEWS (Nov. 8, 2018), <https://www.mdedge.com/obgyn/article/184087/contraception/trump-administration-rule-erodes-aca-contraceptive-mandate> [<https://perma.cc/YSE9-TNNZ>]; Matt Stevens, *Judge Blocks Trump's Attempt to Roll Back Birth Control Mandate*, N. Y. TIMES (Jan. 14, 2019), <https://www.nytimes.com/2019/01/14/us/politics/trump-birth-control-mandate.html> [<https://perma.cc/J4Q5-YDR5>].

¹⁹⁷ West, *supra* note 193, at 1427.

¹⁹⁸ See Elizabeth R. Schiltz, *Finding Common Ground in the Disability Rights Critiques of Selective Abortions*, in *IN SEARCH OF COMMON GROUND ON ABORTION: FROM CULTURE WAR TO REPRODUCTIVE JUSTICE* 117, 117 (Robin West et al., eds. 2014).

common ground in advocating for more governmental support for people with disabilities as a tool to reduce the need for abortion services. It is not necessary for these two movements to be diametrically opposed to each other, and it would be beneficial for both movements to focus on areas where their interests intersect. This kind of intersectionality is helpful, not just at the movement level, but also on a micro level, at the physician-patient relationship level. The next Part transitions to the physician level and examines the opportunities for respecting both reproductive rights and disability rights during physician counseling.

III. BEYOND THE ABORTION/NO ABORTION BINARY: ANALYZING PHYSICIAN GUIDANCE

This article has discussed intersectionality at the movement, macro level. This Part analyzes the public health guidance available to physicians about counseling pregnant women with Zika with a look towards opportunities to finding common ground between disability rights and reproductive justice. This is important because obstetricians may assume a woman would want to terminate a fetus that has shown signs of a significant genetic anomaly. However, it is important from a reproductive justice and disability justice perspective that physicians provide complete information, so that a woman is acting with true procreative liberty. Physicians are bound by the classical bioethical duties of respecting autonomy, beneficence (“to do good”), non-maleficence (“to avoid harm”), and justice (fairness).¹⁹⁹ Each of these principles fit within the contextual intersectional analysis that considers both disability and reproductive justice.

There is “an inherent tension between” promoting reproductive autonomy and preventing children from being born with disabilities.²⁰⁰ Reproductive autonomy in this context means that a woman should be able “to freely choose whether . . . she wishes to give birth to a disabled child.”²⁰¹ Such autonomy in the Zika context means access to contraception, rapid Zika testing, and abortions. Some argue that this “is eugenic in nature, and that the decision to terminate a pregnancy of a child deemed ‘defective’ is ‘morally problematic, and . . . driven by misinformation.’”²⁰² In

¹⁹⁹ See generally TOM L. BEAUCHAMP & JAMES E. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 99–280(6th ed. 2009).

²⁰⁰ Giric, *supra* note 181, at 737.

²⁰¹ *Id.*

²⁰² *Id.* (alteration in original) (quoting Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS* (2000)).

keeping with the privacy rationale of *Roe v. Wade*,²⁰³ the reasons behind a woman's decision to terminate a pregnancy are not legally relevant to accessing abortion services. Rather than restrict access to abortion services, the government should provide more options so that women who decide to continue a Zika-affected pregnancy are provided support, both during pregnancy and throughout the life of the child born with disabilities. Those with disabilities and those raising children with disabilities are vulnerable financially and emotionally and need a supportive framework.

It is helpful to analyze the guidance provided to physicians in light of the novel Zika dilemmas. This section examines the guidance provided by the WHO, ACOG, and the CDC about counseling a pregnant woman with Zika to determine if the guidance took into values important to both the reproductive justice and disability rights movements.

A. ACOG Guidance

As the professional society catering to obstetricians and gynecologists, ACOG's guidance is of primary importance to physicians.²⁰⁴ In advising about how to clinically manage a pregnant woman with Zika, ACOG notes that each situation "should be individualized."²⁰⁵ ACOG requires that a physician acknowledge that there is much uncertainty "about the effects of Zika virus on a fetus."²⁰⁶ ACOG requires a physician to offer "comprehensive options counseling, including a thorough discussion of pregnancy continuation, termination of pregnancy, and adoption. As with all patient counseling, health care providers must not seek to impose their personal beliefs upon their patients nor allow personal beliefs to compromise patient health, access to care, or informed consent."²⁰⁷ This requirement is beneficial from a reproductive justice viewpoint as it gives a woman room to continue or terminate a pregnancy.²⁰⁸ ACOG also notes that "Congenital Zika syndrome—a recently recognized pattern of congenital anomalies associated with Zika virus

²⁰³ *Roe v. Wade*, 410 U.S. 113, 152–54 (1973).

²⁰⁴ *ACOG Mission, Vision, and Core Values*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org/About-ACOG/About-Us/ACOG-Mission-Vision-and-Core-Values> [<https://perma.cc/9LZG-XDC3>].

²⁰⁵ *Clinical Management of a Pregnant Woman with Suspected Zika Virus Infection*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS (Oct. 26, 2017), <https://www.acog.org/About-ACOG/News-Room/Practice-Advisories/Practice-Advisory-Interim-Guidance-for-Care-of-Obstetric-Patients-During-a-Zika-Virus-Outbreak#clinical915> [<https://perma.cc/MRP6-B77D>].

²⁰⁶ *Id.*

²⁰⁷ *Id.*

²⁰⁸ *Id.*

infection during pregnancy that includes microcephaly, intracranial calcifications or other brain anomalies, or eye anomalies, among others—may present well after birth.”²⁰⁹ The physician must inform the woman that normal ultrasound findings do not mean that the fetus does not have or will not have Zika-related anomalies.²¹⁰ Although this standard is wise from a wrongful birth and informed consent perspective, there are problems with it from the disability lens.²¹¹ The unknown can be fear-inducing. Without providing any information about microcephaly support organizations or disability support groups, this advice can be seen as encouraging termination.

B. WHO Approach

The WHO’s approach is somewhat in line with both reproductive justice and disability rights.²¹² In discussing women with Zika, the WHO guidance states “[w]omen who carry their pregnancy to term must receive appropriate care and support to manage anxiety, stress and the birth environment.”²¹³ Additionally, the WHO directs physicians to discuss “[p]lans for care and management of the baby soon after birth . . . with the parents during the pregnancy, in consultation with a [pediatrician] or [pediatric] neurologist.”²¹⁴ From a disability rights lens, directing the physician to include contact information about state and private organizations who can help the woman navigate the realities and unknowns of raising a child with a disability may allow woman to have better information about how to proceed.

The WHO makes clear that “[w]omen who wish to discontinue their pregnancy should receive accurate information about their options to the full extent of the law, including harm reduction where the care desired is not readily available.”²¹⁵ The harm reduction model, used in countries with restrictive abortion laws, involves a physician providing “scientifically based and neutral counseling” about “the risks associated with different means to induce abortion and signs of complications

²⁰⁹ *Id.*

²¹⁰ *Id.*

²¹¹ See generally Mary B. Sullivan, Note, *Wrongful Birth and Wrongful Conception: A Parent’s Need for a Cause of Action*, 15 J.L. & HEALTH 105 (2000) (discussing the need for and issues surrounding wrongful birth, wrongful conception, and wrongful pregnancy claims).

²¹² See WORLD HEALTH ORG., INTERIM GUIDANCE UPDATE: PREGNANCY MANAGEMENT IN THE CONTEXT OF ZIKA VIRUS INFECTION 8–9 (2016), http://apps.who.int/iris/bitstream/10665/204520/1/WHO_ZIKV_MOC_16.2_eng.pdf?ua=1 [<https://perma.cc/2N2P-5KN9>].

²¹³ *Id.* at 8.

²¹⁴ *Id.*

²¹⁵ *Id.* at 9 (footnote omitted).

that require immediate attention.”²¹⁶ “The [physician] is not involved in inducing the abortion, [but] only [is involved] in providing information to help women reduce avoidable harm.”²¹⁷ This is important because “research and experience have shown that where abortion is illegal or highly restricted, women resort to desperate, dangerous means to end unwanted pregnancies, including self-inflicted trauma, consumption of chemicals, self-medication, and even unqualified, untrained and likely unsafe abortion providers.”²¹⁸ The WHO advice seems to fulfill a physician’s duty to provide patient autonomy, by providing comprehensive information.

C. CDC Approach

In the hypothetical at the start of the article, I noted that Dr. Davila might answer Jennelle’s question using the CDC’s approach.²¹⁹ The CDC provided guidance to physicians about how to counsel pregnant patients who may have contracted Zika.²²⁰ Likely due to fear of political fallout, the guidance is silent on abortion, even though ACOG recommends that a physician provide nondirective abortion counseling when a woman infected with Zika is facing the possibility of a fetal malformation.²²¹ Under the CDC guidance, a physician would not even mention

²¹⁶ Paige Baum et al., *Ensuring a Rights-Based Health Sector Response to Women Affected by Zika*, 32 CADERNOS DE SAÚDE PÚBLICA 1, 2 (2016), http://www.scielo.br/scielo.php?pid=S0102-311X2016000500605&script=sci_arttext&tlng=en#B12 [<https://perma.cc/W3C6-K9CU>].

²¹⁷ *Id.*

²¹⁸ ACOG Statement on New England Journal of Medicine Study on Zika and Abortion Requests, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS (June 22, 2016), <https://www.acog.org/About-ACOG/News-Room/Statements/2016/ACOG-Statement-on-New-England-Journal-of-Medicine-Study-on-Zika-and-Abortion-Requests> [<https://perma.cc/H6T4-UUSE>].

²¹⁹ See *supra* notes 1–3 and accompanying text.

²²⁰ See *For Healthcare Providers*, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 12, 2018), <https://www.cdc.gov/zika/hc-providers/index.html> [<https://perma.cc/T9SW-CJC6>]; see also *Caring for Pregnant Women*, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 21, 2018), <https://www.cdc.gov/pregnancy/zika/testing-follow-up/pregnant-woman.html> [<https://perma.cc/6VKQ-MTDT>].

²²¹ See *Clinical Management of a Pregnant Woman*, *supra* note 205. The ACOG site states:

Obstetrician-gynecologists and other obstetric providers should . . . be prepared to counsel pregnant women exposed to or infected with Zika about the virus and their options related to the pregnancy. Like all pregnant women, Zika-infected pregnant women should have full access to the complete range of reproductive options, including termination of pregnancy.

Id.; see also WORLD HEALTH ORG., *supra* note 212, at 9 (emphasizing procreative liberty by noting that “[a]ll women, whatever their individual choices with respect to their pregnancies, must be treated with respect and dignity”).

abortion.²²² The suggested script provides the following suggestion for physicians to relay to their patients: “If you test positive for Zika, I will need to watch your pregnancy more closely. I may do more ultrasounds or other tests to check for your fetus’s growth and development.”²²³ Note, though, that these are the only items mentioned to patients regarding the possibilities after a positive Zika test result.

Unlike the WHO and ACOG’s recommendations to include a discussion of abortion, the CDC avoids this completely, likely for political reasons. The WHO’s guidance on the same topic suggests that a pregnant woman with Zika “should be offered non-directive counseling so that she, in consultation with her health care provider, can make a fully informed choice about the next steps in the management of her pregnancy.”²²⁴ On the other hand, the CDC guidance does not suggest any information that would aid the woman in caring for a baby who may be born with a serious birth defect.²²⁵ States, such as New Jersey, have incorporated the CDC guidelines into their own advisories.²²⁶ Thus, it is worrisome that the CDC guidance strays from the WHO guidance. New York City strayed from the CDC’s approach, and its guidance is more comprehensive than the CDC’s.²²⁷

D. *New York City’s Approach*

The New York City Department of Health’s (NYC DOH)²²⁸ guidance is more comprehensive than either the WHO or the CDC guidance.²²⁹ However, it appears only to contemplate a physician discussing abortion if a woman consults the provider while making the decision to continue or terminate a pregnancy.²³⁰ The guidance suggests that “[p]roviders . . . avoid making assumptions about the woman’s pregnancy intentions and . . . offer the most updated information available about the possible effects of Zika virus

²²² *Pretest Counseling Conversation Guide for Healthcare Providers for Pregnant Women with Symptoms of Zika*, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 25, 2017) [hereinafter *Pretest Counseling*], <https://www.cdc.gov/pregnancy/zika/testing-follow-up/documents/clinician-guide-symptoms.pdf> [<https://perma.cc/296G-M7BU>].

²²³ *Id.* at 2.

²²⁴ WORLD HEALTH ORG., *supra* note 212, at 8.

²²⁵ *See Pretest Counseling, supra* note 222.

²²⁶ *See, e.g., Key Messages—Zika Virus Disease*, N.J. DEP’T OF HEALTH, 16–19, 27–30 (Apr. 6, 2016) https://www.nj.gov/health/cd/zika/documents/cdc_zika_key_msg04062016.pdf [<https://perma.cc/65TR-D2SG>].

²²⁷ *Guidance on Counseling Pregnant Patients with or at Risk for Zika Virus*, N.Y.C. DEP’T OF HEALTH & MENTAL HYGIENE (Sept. 30, 2016), <https://www1.nyc.gov/assets/doh/downloads/pdf/cd/zika-provider-guidance.pdf> [<https://perma.cc/ZE8K-7NAT>].

²²⁸ *Id.*

²²⁹ *See id.* at 9.

²³⁰ *Id.*

infection on pregnancy and provide timely referrals.”²³¹ This is important when considering the impact of Zika from both reproductive justice and disability justice perspective.

A physician should not presume that just because a fetus may have an impairment that the woman would like to terminate the pregnancy.²³² Termination of a pregnancy should be a case-by-case decision for every woman. The NYC DOH emphasizes that “[i]t is critical to communicate that we do not know much about the short- and long-term effects of Zika virus infection on fetal development or pregnancy outcomes. . . . [or] the proportion of Zika affected pregnancies that will result in adverse outcomes for the fetus or neonate.”²³³ The guidance suggests, “[i]f a woman is considering terminating her pregnancy and her regular provider does not perform induced abortions, referral to physicians who perform pregnancy termination should be provided.”²³⁴ The guidance specifies that “[p]regnancy termination is legal, safe and available in NYC up to 23 6/7 weeks of pregnancy,” and provides information about how to refer patients to get information about abortion services across the state and in later term pregnancies.²³⁵ NYC DOH’s guidance is a good starting point, but a woman facing the possibility of having a child with microcephaly should receive more information about what that would entail and what kinds of support are available to her.

IV. PHYSICIAN ADVISING IN THE PREGNANCY CONTEXT: NEED FOR AUTONOMY AND SUPPORT

A woman’s physician plays a pivotal role in medical decision making,²³⁶ and this may be particularly pronounced in the case of an unfamiliar condition such as Zika. In many cases, a physician can greatly influence what decision a woman makes by the information she provides.²³⁷ Due to the panic surrounding Zika, it is likely that a woman exposed to Zika would be fearful about her fetus’ health. Her physician would likely be her first contact about what this means. A physician, with medical knowledge and

²³¹ *Id.*

²³² *See id.*

²³³ *Id.*

²³⁴ *Id.*

²³⁵ *Id.*

²³⁶ Terri R. Fried, *Shared Decision Making—Finding the Sweet Spot*, 374 NEW ENG. J. MED. 104, 104 (2016).

²³⁷ *Id.* (“Physicians describe processes that range from explaining the clinical situation and making a recommendation that the patient can accept or reject to outlining the treatment options and leaving the final decision to the patient. In other words, the leeway and responsibility given to the patient for making the decision can vary widely.” (footnotes omitted)).

“gravitas,” can be an important source of support and information for the patient. Although we have gladly moved passed the “doctor knows best” days, there is a power differential between a doctor and a patient. In these interactions, a physician’s framing of an issue can influence a woman even when the physician is providing nondirective counseling.²³⁸

Abortion jurisprudence fashions abortion as a negative right belonging to a woman, rooted in the concept of privacy.²³⁹ Aziza Ahmed²⁴⁰ contends that feminists who view the zone of privacy “between a woman and her doctor” as an achievement “undermine[] the reproductive justice movement” by ignoring the power of the structured regulatory environments within medical institutions.²⁴¹ The zone of privacy needs to be transformed into a zone of opportunity, so that a woman receives more information to help her navigate her decision.

Ahmed argues that “[c]onceptualizing the clinic as a space that can be regulated generates a range of legal strategies . . . to improve abortion access [that] ‘could [be] buil[t] out of the current political, regulatory, and evidentiary climate.’”²⁴² Ahmed’s recommendation that “states could mandate disclosure by all pregnancy-related providers of the types of services that are available—including whether abortions are available and accessible at the given facility” are particularly important in light of the Zika crisis.²⁴³ Ahmed also suggests that reproductive justice activists could offer providers modified scripts.²⁴⁴ Ahmed’s reproductive justice framework focuses on the institutional level as being “vulnerable” to being shaped by political will and making the zone of privacy “between a woman and her doctor” nothing but a smoke screen.²⁴⁵ When examining the CDC recommendations, it is clear how politics impede the frank conversations between a physician and their patient. Ahmed’s recommendations move the

²³⁸ *Id.* a 104–06 (giving examples of how different forms of counseling may make patients make different decisions).

²³⁹ See ROBERTSON, *supra* note 172, at 23.

²⁴⁰ “Professor [Aziza] Ahmed is an internationally renowned expert in health law, criminal law, and human rights.” She is currently a professor at Northeastern School of Law in Boston, Massachusetts. *NUSL Faculty Directory*, NE. UNIV. SCH. OF L., <https://www.northeastern.edu/law/faculty/directory/ahmed.html> [<https://perma.cc/DA57-KU53>].

²⁴¹ Aziza Ahmed, *Medical Evidence and Expertise in Abortion Jurisprudence*, 41 AM. J.L. & MED. 85, 114–15 (2015).

²⁴² *Id.* at 115.

²⁴³ *Id.*

²⁴⁴ *Id.*

²⁴⁵ *Id.* at 114–15

focus away from privacy, towards regulation as a new way of addressing access for those who are reproductively oppressed.²⁴⁶

Although this article uses Zika as a case study, the same conflicts between reproductive justice and disability rights exist in other types of prenatal testing. Scholars have explored this tension in the realm of non-invasive prenatal testing, genetic testing and counseling, and preimplantation genetic testing.²⁴⁷ Examining this literature elucidates solutions that would be applicable in the Zika context and more broadly. There have been some legislative solutions on the national and state level that attempt to aid in facilitating these types of conversations.²⁴⁸

A. *Intersectionality at the Federal Level: The Prenatally and Postnatally Diagnosed Conditions Awareness Act*

As mentioned earlier, Generations Ahead²⁴⁹ managed to bring together a coalition of reproductive justice and disability rights advocates to attempt to find support for the Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCA).²⁵⁰ The PPDCA was passed in 2008 with bipartisan support.²⁵¹ It enables the Secretary of Health and Human Services to issue grants to organizations that collect information on genetic disorders and assist families raising children with Down syndrome or other prenatally or postnatally diagnosed conditions.²⁵² Microcephaly caused by Zika is an example of a condition that would be covered under the PPDCA.²⁵³ The purpose of the PPDCA was to give prospective parents accurate information so that they could make thoughtful decisions about raising children with certain genetic

²⁴⁶ *Id.*

²⁴⁷ See Anna Piepmeier, *The Inadequacy of "Choice": Disability and What's Wrong with Feminist Framings of Reproduction*, 39 FEMINIST STUD. 159, 164–66 (2013) (discussing genetic testing for Down syndrome); see also Carole J. Petersen, *Reproductive Justice, Public Policy, and Abortion on the Basis of Fetal Impairment: Lessons from International Human Rights Law and the Potential Impact of the Convention on the Rights of Persons with Disabilities*, 28 J.L. & HEALTH 121, 126–34 (2015) (discussing a bill in North Dakota prohibiting abortion when sought for "sex selection" or "genetic abnormality.").

²⁴⁸ See *infra* Section IV.A.–B.

²⁴⁹ GENERATIONS AHEAD, <http://www.generations-ahead.org> [<https://perma.cc/QTZ5-7GEB>]; see *supra* notes 165–170 and accompany text.

²⁵⁰ GENERATIONS AHEAD, BRIDGING THE DIVIDE: DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS AND JUSTICE ADVOCATES DISCUSSING GENETIC TECHNOLOGIES 14–15 (2009), http://www.generations-ahead.org/files-for-download/articles/GenAheadReport_BridgingTheDivide.pdf [<https://perma.cc/G63R-CU6E>].

²⁵¹ Bret D. Asbury, *Fostering Informed Choice: Alleviating the Trauma of Genetic Abortions*, 25 CORNELL J.L. & PUB. POL'Y 293, 297 (2015).

²⁵² Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008, Pub. L. No. 110-374, sec. 3, § 399R(b)(1) 122 Stat. 4051, 4052 (codified as amended at 42 U.S.C. §§ 280g–8(b)(1) (2012)).

²⁵³ Asbury, *supra* note 251, at 297.

disorders.²⁵⁴ The PPDCA was an example of an intersectional effort that brought together anti-abortion, reproductive justice, and disability advocates around the common goal of supporting parents caring for children with congenital diseases.

Unfortunately, this bipartisan victory was in name only. Originally envisioned with a “\$5 million [base] of funding to support its objectives,” the PPDCA passed with no funding provisions.²⁵⁵ It has been underfunded since it passed, and thus the goal to provide women with information prenatally and postnatally has not been met.²⁵⁶ The PPDCA represents the type of legislation that can gain support even with the strongly anti-abortion current administration. If groups like Planned Parenthood and NOW join forces with anti-abortion groups and disability rights groups with whom they are typically in tension, they could exert public pressure to get such legislation funded. The Zika epidemic’s likely resurgence in Puerto Rico demonstrates an opportunity to advocate for such an effort.²⁵⁷ Zika is an ailment that can affect anyone exposed to a mosquito carrying the virus, and it is possible that this universal vulnerability can be utilized to rally support from disparate groups to fund the PPDCA.

B. *State Efforts: Down Syndrome Specific Laws*

Many states have attempted to do what the PPDCA could not—support more informative conversations about certain genetic conditions. For example, Chloe’s Law (officially the Down Syndrome Prenatal and Postnatal Education Act) requires that a physician who orders a test for Down syndrome to a pregnant woman or new parent, and upon receiving a test result that is positive for Down syndrome, provides that person with educational information and contact information about support services on the Department of Health website in language that is understandable by the lay public.²⁵⁸ This educational information includes “up-to-date, evidence-based, printed information about Down syndrome that has been reviewed by medical experts and

²⁵⁴ *Id.* at 297, n.14 (citing 122 Stat. 4051).

²⁵⁵ *Id.* at 314 (citing Prenatally and Postnatally Diagnosed Conditions Awareness Act, S. 1810, 110th Cong. (as introduced July 18, 2007)).

²⁵⁶ Asbury, *supra* note 251, at 314.

²⁵⁷ See Beth Murphy, *What’s the Truth About Zika Virus in Post-Hurricane Puerto Rico*, PBS NEWSHOUR (Nov. 14, 2018, 6:15 PM EST), <https://www.pbs.org/newshour/show/whats-the-truth-about-zika-virus-in-post-hurricane-puerto-rico> [<https://perma.cc/F97B-SCTR>].

²⁵⁸ Down Syndrome Prenatal and Postnatal Education Act, 2014 Pa. Legis. Serv. Act 2014-130 (H.B. 2111) (Purdon’s) (codified at 35 PA. STAT. AND CONS. STAT. ANN. § 6244 (West 2014)).

national Down syndrome organizations.”²⁵⁹ The educational information provided includes: “(i) Physical, developmental, educational and psychosocial outcomes; (ii) Life expectancy; (iii) Clinical course; (iv) Intellectual and functional development; [and] (v) Treatment options.”²⁶⁰

Arthur Caplan argues that the law “seeks to spin the message given by doctors and counselors about Down syndrome in a particular direction.”²⁶¹ Caplan is correct that the supporters of Chloe’s Law are directed specifically to associations that are pronatalist under the law. However, providing value-neutral educational information would be helpful and consistent with an intersectionality approach. Additionally, nothing in the Act requires positive counseling to convince a woman to progress with her pregnancy.²⁶² Directive counseling does not mean not providing any information about living with the condition. The organizations and groups that helped approve the information about Down Syndrome include advocacy groups whose members have experience with Down Syndrome in their families.²⁶³ If a woman decides to contact an organization from a website, she is empowering herself with information that she desires. No one ought to compel a woman to read or access the information if she does not choose to do so. However, quite often, a woman may not even know that such organizations exist.

Some critique the binary nature of prenatal testing for a congenital abnormality: meaning your fetus tests either positive or negative for a certain ailment.²⁶⁴ Depending on the disease, a positive test does not mean one cannot have a positive life. Most physicians and genetic counselors do not go into nuanced discussions of what a potential life with that disorder may be.²⁶⁵ Due to concerns about potential wrongful birth claims, it is possible that physicians present a more dire scenario than necessary to ensure that they can document that they have informed the pregnant woman of a “worst-case scenario,” rather than a range of possibilities.²⁶⁶ The basis of wrongful birth claims is a woman would

²⁵⁹ 35 PA. STAT. AND CONS. STAT. ANN. § 6244(a)(1) (West 2014).

²⁶⁰ *Id.* § 6244(a)(1)(i)–(v).

²⁶¹ Arthur L. Caplan, *Chloe’s Law: A Powerful Legislative Movement Challenging a Core Ethical Norm of Genetic Testing*, 13 PLOS BIOLOGY 1, 3 (2015), <http://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.1002219> [<https://perma.cc/7WYR-EQQAQ>].

²⁶² 35 PA. STAT. AND CONS. STAT. ANN. § 6244.

²⁶³ *Id.*

²⁶⁴ Asbury, *supra* note 251, at 301.

²⁶⁵ *Id.* at 301–02.

²⁶⁶ For example, one mother with two children with microcephaly was told that her daughters would likely only live one year. At the time of her interview, her daughters were ten and fifteen years old. See Colby Itkowitz, *What This Amazing Mom of Two Girls with Microcephaly Has to Say About Zika Scare*, WASH. POST (Feb. 3, 2016), <https://>

have terminated her pregnancy had she known or understood the problems that occurred with her pregnancy. This creates incentives for physicians to test for and focus on negative outcomes.

Although the impetus behind Chloe's Law is sympathetic, it is lacking due to its singular focus on Down syndrome. To date, six other states have laws similar to Chloe's Law—Ohio, Maryland, Delaware, Louisiana, Kentucky, and Massachusetts all focus specifically on Down syndrome and require similar information as Pennsylvania does.²⁶⁷ Kentucky's law includes information on both Down syndrome and spina bifida.²⁶⁸ Just as an intersectional analysis needs to take into account race, gender, class, it should also take into account types of disability. Although published statistics vary, anywhere from seventy-five to ninety-two percent of women who receive information that their fetus has Down syndrome terminate the pregnancy.²⁶⁹ By only requiring information about the most common genetic disorder, it sends an expressive message that if you are going to have a less than perfect child, hopefully it will have Down syndrome and not the hundreds of other genetic disorders that do not have a cadre of support around them. This type of Act can and should be expanded to include a whole host of common congenital disorders. Legislation of this nature can build bridges between reproductive rights and disability rights in the medical counseling arena.

Some states have passed laws to broaden their prenatal counseling beyond Down syndrome. For example, Missouri law requires that:

www.washingtonpost.com/news/inspired-life/wp/2016/02/03/what-this-amazing-mom-of-two-girls-with-microcephaley-has-to-say-about-zika-scare/ [<https://perma.cc/7PA3-5HW6>].

²⁶⁷ Asbury, *supra* note 251, at 315–16 (citing DEL. CODE ANN. tit. 16, § 801B (2014); KY. REV. STAT. ANN. § 211.192 (2013); ; LA. REV. STAT. ANN. § 40:1300.392 (2014); MASS. GEN. LAWS ANN. ch. 111, § 70H (2012)); 119 MD. CODE ANN., HEALTH-GEN. § 20-1502 (2014);; OHIO REV. CODE ANN. § 3701.69(A)(1)-(2) (2014)).

²⁶⁸ *Id.* at 316 (citing KY. REV. STAT. ANN. § 211.192 (2013)).

²⁶⁹ See *New Study: Abortion After Prenatal Diagnosis of Down Syndrome Reduces Down Syndrome Community by Thirty Percent*, CHARLOTTE LOZIER INST. (Apr. 21, 2015), <https://lozierinstitute.org/new-study-abortion-after-prenatal-diagnosis-of-down-syndrome-reduces-down-syndrome-community-by-thirty-percent/> [<https://perma.cc/2KT4-UVQC>] (“While new data suggesting lower numbers has recently been published, we continue to see most often in print a statistics of 90–92%. While that certainly draws attention to the horrifying reality that the majority of children prenatally diagnosed with DS are aborted, it is not accurate.”); see also Ruth Graham, *Choosing Life with Down Syndrome*, SLATE (May 31, 2018, 5:57 AM) <https://slate.com/human-interest/2018/05/how-down-syndrome-is-redefining-the-abortion-debate.html> [<http://perma.cc/YT2L-7J84>] (“In many parts of Europe, including the United Kingdom, the termination rate after a prenatal Down syndrome diagnosis is now more than 90 percent. . . . In the United States, screening is not as widespread, but about three-quarters of women who do receive a prenatal diagnosis of Down syndrome terminate the pregnancy, according to a survey of recent studies published in 2012.”).

when a prenatally diagnosed condition, including but not limited to Down Syndrome, becomes known as a result of one or more prenatal tests, the physician or other health care professional who requested or ordered prenatal tests, or his or her designee, *shall* provide the patient with current information about the conditions that were tested for, the accuracy of such tests, and resources for obtaining support services for such conditions, including information hotlines specific to Down Syndrome or other prenatally diagnosed conditions, resource centers, and clearinghouses for such conditions, support programs for parents and families, and the alternatives to abortion services program.²⁷⁰

Missouri's statute would require a physician like Dr. Davila in the earlier hypothetical to provide all current information about microcephaly and provide access to resource centers and support programs-and alternatives to abortion services.²⁷¹ Viewed alone, Missouri's statute fulfills the goal of disability rights by allowing a woman to gather information about the ailment for which her fetus may have tested positive. However, it fails from a reproductive justice perspective, as it does not require any conversation about reproductive options.

C. *Guidance Should Include Counseling About Raising a Child with a Disability*

The sample Zika guidance from public health agencies, departments, and ACOG make clear that in each sample conversation, there is a missing discussion about raising a child with a disability.²⁷² From the perspective of reproductive justice, a woman should have as much opportunity, information, and support to birth a child with a disability as to terminate her pregnancy. The whole point of reproductive justice is to move the discourse beyond abortion.²⁷³ However, the CDC does not even mention abortion as an option in the guidance to physicians, which is contrary to ACOG and WHO advice. Even the WHO and ACOG, however, only go as far as providing the information that termination is an option.²⁷⁴ True reproductive freedom would mean that a pregnant woman with Zika would be supported throughout a difficult pregnancy and be counseled about raising a child who may have a serious birth defect. This counseling may involve explaining the condition in simple terms, not highfalutin medical lingo.²⁷⁵ In the case of Zika, a woman may face the

²⁷⁰ MO. REV. STAT. § 191.923(3) (2007) (emphasis added).

²⁷¹ See *supra* note 1 and accompanying text.

²⁷² See *supra* Part III.

²⁷³ See *supra* Section II.B.

²⁷⁴ See *supra* notes 220–221.

²⁷⁵ Some hospitals provide easy to understand coloring books to parents about their child's condition, developed after conversations with parents about what information

dilemma of not knowing whether her child will be affected by microcephaly at the same time she needs to make a decision about whether to carry her pregnancy to term.²⁷⁶

The discussion of raising a child with a disability at the time when a woman has not decided whether to continue with the pregnancy may be seen as trying to unduly influence women. However, there is a distinction between this article's recommendation and those of the scores of anti-abortion activists who have continually tried to change state laws to require women who have already decided to have an abortion to watch undergo invasive vaginal ultrasounds and be forced to look at the ultrasounds in an attempt to have them change their minds.²⁷⁷ In those cases, the woman has already decided to have an abortion and is at a clinic to get the procedure. My proposal is that doctors should include a discussion about disability made at the time of Zika or microcephaly diagnosis to help with decision-making. Given the lack of gynecologists who perform abortions, which itself is a reproductive justice problem, it is unlikely that a woman's primary care physician who discovers her pregnancy would be the one who will perform the abortion should she decide to terminate her pregnancy.²⁷⁸

they would have liked. Although that may seem simplistic, it is a way of ensuring that the patient can understand what their child will face. *Beckwith-Wiedemann Syndrome*, CHILDREN'S HOSP. OF PHILA., <http://www.chop.edu/conditions-diseases/beckwith-wiedemann-syndrome> [<https://perma.cc/KQZ9-6QGY>] ("Developed through conversations with families of children with Beckwith-Wiedemann Syndrome (BWS), this coloring book includes simple illustrations and easy-to-understand descriptions of the genetic and epigenetic causes of BWS, as well as information on managing BWS."); see JENN KALISH & RACHEL OTTMAN, CHILDREN'S HOSP. OF PHILA., *BWS AND YOU: AN EDUCATIONAL COLORING BOOK* (Sophie Kalish-Schur et al. eds., 2016).

²⁷⁶ For example, in one study of women who had continued their pregnancy after receiving a positive Down syndrome diagnosis, the majority of women who received written materials about Down syndrome felt more positive about their experience and better equipped with information. See Brian G. Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers*, 192 *Am. J. Obstetrics & Gynecology* 670, 674 (2005).

²⁷⁷ Dahlia Lithwick, *Virginia's Proposed Ultrasound Law Is an Abomination*, SLATE (Feb. 16, 2012, 6:57 PM), <https://slate.com/human-interest/2012/02/virginia-ultrasound-law-women-who-want-an-abortion-will-be-forcibly-penetrated-for-no-medical-reason.html> [<https://perma.cc/KX9A-4HMQ>]; see also S.B. 484, 2012 S., Reg. Sess. (Va. 2012); see also *State Laws And Policies: Requirements for Ultrasound*, GUTTMACHER INST. (Mar. 1, 2019), <https://www.guttmacher.org/state-policy/explore/requirements-ultrasound> [<https://perma.cc/65V9-RJRN>] ("Since routine ultrasound is not considered medically necessary as a component of first-trimester abortion, the requirements appear to be a veiled attempt to personify the fetus and dissuade a woman from obtaining an abortion. Moreover, an ultrasound can add significantly to the cost of the procedure.")

²⁷⁸ Am. Coll. of Obstetricians & Gynecologists, Comm. on Health Care for Underserved Women, Comm. Op. 613, *supra* note 109 (noting the "restricted pool of health professionals qualified and willing to provide abortion care."). Rebecca Wind, *Most U.S. Obstetrician-Gynecologists in Private Practice Do Not Provide Abortions and Many Also Fail to Provide Referrals*, GUTTMACHER INST. (Nov. 27, 2017) <https://www.guttmacher.org/news-release/2017/most-us-obstetrician-gynecologists-private-practice-do-not-provide-abo>

Many medical professionals went into their fields to help “save lives” or “make people healthy.” Therefore, they may be biased by their training or nature to discouraging a woman to continue a pregnancy when she is carrying a fetus that may have a congenital abnormality. Even though the WHO and ACOG suggest nondirective counseling about termination,²⁷⁹ a physician’s medical lens necessarily biases the discussion a physician has with women. I suggest that disability rights-focused training modules be made part of the medical school curriculum. However, even if that becomes more standard, physicians should be required to provide information to pregnant women about disability support groups and organizations that can provide another perspective to the woman. More systematic training for physicians should be provided in medical school about how to discuss disability with patients. As a part of the medical educational process, disability rights’ groups should be involved in allowing physicians to hear about perspectives from people with disabilities. Information from disability support organizations should be provided in the form of websites, pamphlets, phone numbers, as a part of nondirective counseling.

In any medical scenario, it is important that physicians are giving advice that provides complete information. In the case of Zika, combining the ACOG language with the language quoted above in the Missouri statute would allow values of both movements to be respected which would result in a more informed decision for the patient.²⁸⁰ The suggested template could be similar to this:

Pregnant women who have been infected with Zika should be advised that congenital Zika syndrome—a pattern of congenital anomalies associated with Zika virus infection during pregnancy that includes microcephaly, intracranial calcifications or other brain anomalies, or eye anomalies, among others—may present during ultrasound, at birth, or well after birth. The physician must inform the woman that normal ultrasound findings do not mean that the fetus does not have or will not have Zika related anomalies. Pregnant women with Zika who are concerned about the health of their fetuses should be offered comprehensive options counseling, including a thorough discussion of pregnancy continuation, termination of pregnancy, and adoption. As with all patient counseling, health care providers must not seek to impose their personal beliefs upon their patients nor allow personal beliefs to compromise patient health, access to care, or informed consent. The physician, or his or her designee, shall provide the patient with current information about Congenital Zika Syndrome and resources for obtaining

rtions-and [https://perma.cc/V7Y9-9QCU] (“Only 7% of U.S. obstetrician-gynecologists who work in private practice settings provided abortions in 2013 or 2014 . . .”).

²⁷⁹ See *supra* note 221.

²⁸⁰ See *Clinical Management of a Pregnant Woman with Suspected Zika Virus Infection*, *supra* note 205; see also MO. REV. STAT. § 191.923(3) (2007).

support services for conditions such microcephaly, including information hotlines specific to these conditions, resource centers, and clearinghouses for such conditions, and support programs for parents and families raising children with disabilities.

Such a template respects both reproductive autonomy and disability rights.

CONCLUSION

A physician's counseling can support a woman's decision-making process when she is facing the potential of raising a child with microcephaly or more broadly, any congenital disorder. When Jennelle asked Dr. Davila, "Doctor, what does this mean?", Dr. Davila likely would have followed the CDC guidelines as suggested. He would not have mentioned abortion. He would not have given Jennelle resources with information about microcephaly. I suggest that public health agencies, at the state and national level, combine ACOG's approach of nondirective abortion counseling and take cues from state legislative efforts to counsel parents about prenatal care about disability.

Although not the focus of this article, medical schools need to incorporate intersectional education to help influence physician attitudes about disability and reproductive justice. If Dr. Davila had been trained during medical school to view disability as an inevitable part of life if you live long enough, and been exposed to disability rights focused modules, he may have been more open in the discussion about what Jennelle's options are.

Finally, both private insurance and government-funded insurance, which are both key to supporting reproductive justice and disability rights, need to be expanded to include abortion funding as an essential health benefit and expand Medicaid funding to support those who live with disabilities or who are taking care of people with disabilities. Coalition building between the reproductive justice and disability rights movements may be possible to advance these goals. I cede that without robust government programs and health insurance protections that provide comprehensive insurance coverage of women's health, women facing the prospect of prenatal genetic anomalies will face much difficulty. In the current political climate, health reform proposals suggest that both women's autonomy and the needs of people with disabilities are at risk. Without such support, no amount of information provided by physicians or private parties will overcome the stigma against both disability and abortion.