

Reproductive Genetic Medicine in a Post-*Dobbs* World: Will it Make Life Harder for People with Genetic Disease?

Sonia M. Suter¹
and Laura Hercher²

1: GEORGE WASHINGTON UNIVERSITY LAW SCHOOL, WASHINGTON, DC, USA; 2: SARAH LAWRENCE COLLEGE, BRONXVILLE, NY, USA.

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Abstract: Post-*Dobbs* abortion restrictions impact access and choice in the context of reproductive genetic medicine, raising serious reproductive justice concerns. The consequences of these restrictions are particularly acute and far-reaching for individuals with genetic conditions and their families.

In 2013, when *Roe v Wade*¹ still guaranteed a constitutional right to abortion, North Dakota passed a law prohibiting providers from knowingly performing abortions motivated solely by a prenatal diagnosis of “a genetic abnormality or a potential for a genetic abnormality.”² By 2022, 13 other states had enacted similar laws.³ In passing these laws, the anti-abortion movement proclaimed itself a champion of people with genetic conditions, and in 2019, Justice Clarence Thomas praised them as necessary antidotes to “modern day eugenics”⁴ (as discussed by Paul Lombardo in this symposium). In fact, *Dobbs v. Jackson Women’s Health Organization*,⁵ which now allows states to ban all abortions including “eugenic abortions,” presages a harder life for those affected by genetic conditions and their families.

This new reality results from the simultaneous occurrence of 1) state-specific abortion restrictions and 2) advancements in genetic medicine that are rapidly increasing our ability to identify genetic risks before or during pregnancy. Despite longstanding concerns about some uses of genetic testing, prospective parents have embraced these technologies. Tests that examine parental and fetal DNA have become multibillion-dollar markets.⁶ But, such routine prenatal care may no longer be available to everyone post-*Dobbs*.

This article begins with an overview of reproductive genetic testing, genetic counseling, and the legal landscape relevant to reproductive genetics. It then discusses how these laws will impact genetic counseling, pregnant people, and those who want to become pregnant. Finally, we show how the post-*Roe* world will

Sonia Suter, J.D., M.S., is a Professor of Law, the Founding Director of the Health Law Initiative at the George Washington University Law School, the Kahan Family Research Professor, and the Henry St. George Tucker III Dean’s Research Professor of Law; **Laura Hercher, M.A., M.S., C.G.C.,** is Director of Student Research at the Sarah Lawrence College Joan H. Marks Graduate Program in Human Genetics.

hurt the very groups the anti-choice abortion movement claims to support — those with genetic conditions and their families.

Reproductive Genetic Testing

Reproductive genetic testing can occur both before and during pregnancy and can involve analysis of DNA from prospective parents, the fetus, and embryos created through in vitro fertilization (IVF). Carrier screening identifies individuals who are at increased risk of having children with a genetic condition, though they themselves are unaffected or minimally affected. Historically such screening was ancestry-based, targeting specific conditions in populations more likely to carry certain disease genes. Today, however, professional organizations recommend universal carrier screening,⁷ and an increasing number of providers offer expanded carrier screening panels, which use new technologies to look for dozens or even hundreds of conditions.⁸

Preimplantation genetic testing of embryos (PGT)

cell-free fetal DNA in the maternal serum.¹³ Typically offered between 10 and 12 weeks' gestation, NIPT has increased the likelihood of finding a limited number of chromosomal conditions, including trisomy 21 (Down syndrome). It does not present the risks associated with invasive procedures.¹⁴ NIPT also offers a platform to expand prenatal testing; many versions of NIPT test for conditions caused by small deletions or duplications in fetal DNA. While NIPT may someday replace diagnostic testing, it is still a screening test; therefore, diagnostic follow-ups are recommended when patients test positive.

Finally, later in pregnancy patients are offered a detailed ultrasound, or anatomy scan. Performed around 20 weeks, this scan identifies observable congenital anomalies.¹⁵

Genetic Counseling

Reproductive genetic counselors work with obstetricians and other health care providers to offer patients a personalized assessment of the likelihood that inher-

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is possible for individuals using IVF, as Judith Daar describes in this symposium. PGT-A, which screens for chromosomal anomalies, is used in more than 40% of IVF cycles.⁹ Another form called PGT-M can be used to identify embryos that carry genes associated with genetic diseases or susceptibilities.

Once people become pregnant, diagnostic genetic testing of the fetus is possible. Chorionic villus sampling and amniocentesis, performed in the first and second trimesters respectively, but not before 10 weeks' gestation, were developed decades ago.¹⁰ Both are invasive with a small increased risk of pregnancy loss.¹¹

Prenatal screening has been offered since the 1970s to identify fetuses at heightened risk for chromosomal anomalies. Newer tests are far less likely to miss affected fetuses and relatively less likely to present false positives.¹² The most powerful screening test is noninvasive prenatal testing (NIPT), which analyzes

ited or acquired genetic differences might impact their health or that of their future child. Obtaining family, medical, and pregnancy history, including prior pregnancies and pregnancy losses, is a routine part of such counseling. Based on this information, genetic counselors discuss the benefits, limits, and risks of various tests so patients can make genuinely informed choices about what is right for them.¹⁶

For example, if carrier testing indicates a 25% chance of a particular genetic disorder, genetic counselors will discuss a variety of options: accepting the risk, adoption, using a gamete donor, IVF with PGT, prenatal testing, or not having children. For those who choose to test prenatally, counselors will explain that the information can help parents plan for the delivery and care of an affected child or give them the option to terminate the pregnancy.

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The Legal Landscape After Dobbs

The Supreme Court in *Dobbs* declared that abortion regulations can stand if they “serve legitimate state interests,” including “respect for and preservation of prenatal life at *all* stages of development,”¹⁸ but it did not address whether exceptions to preserve maternal life or health or fetal anomalies are required.

Today, the legal landscape is highly variable, with states at one extreme imposing near complete or early bans, and states at the other extreme offering broad access to abortion without gestational age limits.¹⁹ Many states impose severe criminal penalties against providers, which, in some states, include life in prison,²⁰ \$100,000 in fines,²¹ and/or action against licensure.²² So far, abortion bans do not allow for prosecution of pregnant individuals. Most abortion bans have no exceptions for rape, incest, or maternal health.²³ A few states have exceptions for lethal fetal anomalies, but none for non-lethal anomalies.²⁴

In 2021, Texas passed SB-8, creating the risk of civil liability for providers and anyone who knowingly engages in or intends to “engage in conduct that aids or abets the performance or inducement of an abortion.”²⁵ This bounty-hunter law allows the whistleblower to recover \$10,000 in damages and attorneys' fees.²⁶ Oklahoma enacted similar legislation.²⁷ These statutes define aiding and abetting to include “paying for or reimbursing the costs of an abortion through insurance or otherwise, ... regardless of whether the person knew or should have known that the abortion would be performed or induced ... ”²⁸

Some scholars suggest that “aiding and abetting” applies only to abortion providers practicing under a license issued in the state.²⁹ Other experts believe many others are at risk: nonprofit funding groups and their donors, employers who help pregnant workers travel for abortions, clinics and their employees, and those who assist in self-managed abortion (as discussed by Skuster in this symposium).³⁰ The National Right to Life Committee (NRLC) Post-*Roe* Model Law takes an aggressive view, deeming it essential to go after the “whole criminal enterprise” by imposing *criminal* penalties on those “conspiring to cause, or aiding or abetting, unlawful abortions,” which includes providing information about abortions.³¹ In short, uncer-

tainty regarding criminal or civil liability for aiding and abetting abortions abounds.

While the legal landscape will remain fluid regarding abortion rights for some time, one certainty is that, absent a highly unlikely national ban, we will continue to see wide discrepancies in abortion laws across the country. Of course, as was true before *Dobbs*, geography will not limit access for those with means. Instead, reproductive justice concerns have grown with abortion bans acting as barriers primarily for those with the fewest resources, who are often people of color, young, and people with disabilities.

The Impact of Dobbs on Genetic Counseling and Reproductive Genetic Testing

While it is too early to assess the full impact of abortion restrictions on reproductive genetic testing and genetic counseling, we do have empirical data on the effects of SB-8. One study of Texas physicians and genetic counselors who provide prenatal care found that the law chilled their behavior.³² While some providers still offer abortions for health risks, including fetal anomalies, as they did in the past, others no longer provide abortions or referrals in many instances.³³

Another study, conducted by one of us in 2021, interviewed genetic counselors in Texas and other states with abortions restrictions.³⁴ Even in states without complete bans, some genetic counselors said they encouraged genetic testing and anatomy scans earlier than recommended to ensure patients had time to obtain an abortion if anomalies were detected.³⁵ Unfortunately, this can potentially result in missed or misleading information. Genetic counselors also described how time pressures affected patients, some of whom obtained abortions after prenatal screening results were positive, without waiting for confirmatory testing, thereby risking the termination of a healthy pregnancy.³⁶

In the few states with exceptions to abortion bans for lethal anomalies, the application of these exemptions is limited by the difficulty in determining whether, for example, a diagnosis is “incompatible with sustaining life after birth.”³⁷ In almost all cases, there is variability in how serious anomalies manifest. To avoid liability, genetic counselors feel pressured to construe those exceptions narrowly, making them inapplicable for most fetal anomalies.

Interviews with genetic counselors in Texas revealed how SB-8 threatens the relationship of trust between counselor and patient that is central to genetic counseling. In their article exploring how medical caregivers can to limit legal liability for themselves and their patients, law professors Michelle Mello and Kayte

Spector-Bagdady caution against relying on email and text: “Generally, legally complex conversations are best conducted in person or by phone.”³⁸ But genetic counselors working under SB8 expressed concerns about “the possibility of secretly recorded phone calls.”³⁹

Fears about legal liability may also lead to self-censorship. Genetic counselors expressed concerns about what they can say about abortion, even when laws do not explicitly prohibit discussions of abortion,⁴⁰ as the NRLC Post-*Roe* Model Law would. Genetic counselors may silence themselves in the face of laws that target aiding and abetting. As one prenatal genetic counselor said, “the [SB-8] language of aiding and abetting ... implicates genetic counseling. We’re not going to counsel patients about an option that’s not available legally.”⁴¹

Today, genetic counselors are forced to reevaluate what they should put in the medical record. As noted, prenatal genetic counseling includes questions about past pregnancies and outcomes. It may also involve prompting patients to discuss their attitudes toward abortion, which can influence decisions about prenatal testing. All of this information typically goes into the medical record. Genetic counselors (and patients) worry that such information could be subpoenaed to support prosecutions of providers or patients. A recent article written by one of us quotes a genetic counselor from Texas who “has already noticed some patients not wanting to fill out the intake forms for pregnancies.”⁴² In a survey of 120 prenatal genetic counselors practicing in the U.S. done by one of us in 2023, 84% of participants reported that post *Dobbs* they had discussed concerns with colleagues about what should go in the medical record, and 50% of them reported that they have altered practice as a result. Over half of all participants reported that their patients had become somewhat or much more reluctant to share information about their current pregnancy.⁴³ Genetic counselors have also recounted their hesitation to document out-of-state abortion procedures.⁴⁴

Even information about miscarriages could pose risks. The medical term for miscarriage is spontaneous abortion,⁴⁵ and it is generally impossible to distinguish miscarriages from medically induced abortions. Thus, prosecutors suspecting abortion may seek information related to all pregnancy loss. To date, the HIPAA privacy rule provides limited protection. For example, it permits but does not require covered entities to disclose personal health information without the individual’s authorization for certain law enforcement purposes or if a court order or a state law demands it.⁴⁶ To ensure enforcement of abortion bans, states might require disclosure of information regard-

ing pregnancy losses to help investigators identify medical abortions.

As Judith Daar describes in this symposium, *Dobbs* also raises the prospect of state laws criminalizing routine aspects of IVF, including destruction of excess embryos or embryos with disease-causing genetic mutations detected through PGT. She and others note that politics, not the constitution, are the only barrier against such laws.⁴⁷

States might also pass legislation to protect what the Supreme Court called a legitimate state interest in preventing “discrimination on the basis of race, sex, or disability.”⁴⁸ They might restrict certain types of prenatal tests to discourage what Justice Thomas and state legislatures have called “eugenic” abortions — abortions based on race, sex, or fetal anomaly.⁴⁹ Or they might provide legal cover for physicians who choose not to disclose the results of prenatal tests for conditions like Down syndrome. In most states, physicians can be liable for wrongful birth for not sharing this information with patients, but a growing number of states prohibit these claims.⁵⁰

Again, political realities make it highly unlikely that states will ban prenatal tests. Like IVF, these tests are popular products of profitable industries. But one could easily imagine states restricting funding for prenatal testing, as some politicians have proposed,⁵¹ which would disproportionately impact low-income individuals. High costs and spotty insurance coverage put IVF and PGT beyond the reach of most Americans and inaccessible to Medicaid beneficiaries.⁵²

The reality is that the post-*Dobbs* world will create two different tracks of prenatal care depending on geography. In states without significant abortion restrictions, patients will have legal access to the full spectrum of medically recommended reproductive genetics care: genetic counseling, carrier screening, prenatal testing, 20-week anatomy scans, IVF, and PGT (if they can afford it), and the ability to terminate based on genetic anomalies. In states with severe abortion restrictions, all of this care is at risk to some degree. Individuals with means — wealth, education, and support — will be able to circumvent restrictions wherever they live because they can pay out of pocket or travel to another state that provides those services. In essence, reproductive justice concerns will hit hard with respect to access to 21st century reproductive genetic medicine, which will depend on where you live, but only for those without resources.

Implications for People with Genetic Diseases and Their Families

Despite the claims of Justice Thomas and others that “eugenic” abortions harm individuals with genetic conditions, individuals with genetic conditions and their families need reproductive liberty and justice as much as or more than anyone else. As Leslie Francis notes in this symposium, pregnancy can be dangerous for those with disabilities and the burden of parenting a sick or special-needs child can also fall heavily on those with their own health issues or on parents facing the prospect of a second affected child. People with genetic conditions and their family members often use genetic testing to minimize recurrence risk.

Second, as demonstrated above, whether one has a full spectrum of choices to address one’s genetic risk now depends on geography and wealth. That has implications for the demographics of genetic diseases, with a potentially profound impact on individuals with genetic conditions, their families, and those with an increased chance of having children with such conditions.

While it is too early to know the full impact, we can predict likely outcomes based on data on the demographic effects of prenatal testing for Down syndrome, the condition most commonly associated with prenatal testing. The most complete meta-analysis of termination rates after receiving a prenatal diagnosis of Down syndrome shows that 67% of prospective parents terminate the pregnancy. But termination rates are not uniform. As Natoli et al. note, “a summary termination rate may not be applicable to the entire US population” because these rates and therefore the incidence of Down syndrome vary by culture and location.⁵³ For example, the prevalence of Down syndrome is incredibly low in wealthy and mostly white communities on Manhattan’s Upper East Side but much higher among Hispanic populations.⁵⁴ While the risk of Down syndrome does not distinguish between these groups, demographic factors influence its prevalence.

Of course, Down syndrome is not a good proxy for other genetic diseases. People with Down syndrome and their families have made it clear that their quality of life is good.⁵⁵ In contrast, some other genetic conditions lead to limited or poor quality of life and early death. Nevertheless, it is not a wide stretch to infer from this study that the added demographics of a state’s abortion laws will also lead to variable rates of children born with other genetic conditions.

The most obvious impact of significant abortion restrictions will be severe limitations on the ability to act on prenatal testing information, making the value of such testing moot for many who would choose to

terminate. Families with a known risk — like parents who already lost a child and face the risk of such loss again — will have no legal recourse to abortion and may face limited access to some forms of prenatal or preconception testing. Of course, not all future parents want that choice. But removing choice for everyone in a particular locale, especially those without the resources to circumvent restrictions, is a serious loss for families struggling to have a healthy child. But the implications for all affected families go beyond recurrence risk.

First, restricting the ability of families without the resources to obtain an abortion and further restricting access to IVF will mean that a greater percentage of affected children are born to those least able to afford the added care and resources these children require. It also means that what was once a random event — the birth of a child with a genetic condition — will now reflect demographic characteristics like geography, culture, and socioeconomic status. Families with children who have genetic conditions need more than just reproductive rights. They need expensive medical care, social support, research programs, advocacy, and social awareness about their children’s challenges. They have long struggled to get such support, even when everyone’s child was potentially at risk — i.e., when there was a commonality of interests. But post-*Dobbs*, the world will be divided by those with and without full reproductive choice.

In states with severe reproductive restrictions, affected children will be disproportionately born to families of low socioeconomic status and other vulnerable groups. These states already provide the fewest resources for families in need.⁵⁶ The resulting association of genetic disease with struggling or marginalized communities may increase stigma. Meanwhile, those best positioned to galvanize political will on behalf of a disease community, or to direct money and attention to these families, are the most likely to have access to and to use reproductive genetic medicine. Evidence shows that those with power, wealth, and personal interest influence policies regarding research, treatment, and support.⁵⁷ What will happen to the disease communities when this class of persons loses interest in playing the role of advocates and fundraisers?

For all these reasons, we anticipate that the disparities in access to reproductive genetic care will not achieve anti-eugenic or anti-discriminatory goals; they will do the opposite. Tellingly, many states that ban abortions based on genetic anomalies, allegedly to combat eugenics or discrimination, are not concerned about other kinds of eugenic or discriminatory policies.⁵⁸ Moreover, restrictions on reproduc-

tive rights are not “part of a broader disability rights policy agenda”⁵⁹ and do not advance disability rights generally. They do not promote the birth of children with genetic conditions by offering support that would make those choices viable or more palatable.⁶⁰ Instead, the disability rights rhetoric used to justify reproductive restrictions politicizes and hinders coalition building on behalf of the disability community.⁶¹ Dividing the country into zones with and without access to reproductive genetics will harm rather than help those with genetic conditions and the people who love them.

Note

The authors have no conflicts to disclose.

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 59. N. Roesner et al., “Reason-Based Abortion Bans, Disability Rights, and the Future of Prenatal Genetic Testing,” *American Journal of Law and Medicine* 48, no. 2-3 (2022): 187-199, <https://doi.org/10.1017/amj.2022.21>.
 60. Professors Rebouche and Rothenberg hinted at these concerns in 2012 in a piece that discussed the implications of “diminishing option of abortion for many pregnant women” while prenatal genetic testing options increase. They warned that “without careful consideration of how prenatal testing and abortion intersect, policy debates may be co-opted by anti-abortion rhetoric, rather than focus on the implications for health care delivery.” R. Rebouche and K. Rothenberg, “Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion,” *Howard Law Journal* 55, no. 3 (2012): 983-1023.
 61. Roesner et al., *supra* note 59, at 11–18.