Preimplantation Genetic Testing: A Fundamental Right

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PREIMPLANTATION GENETIC TESTING:
A FUNDAMENTAL RIGHT

ABSTRACT

Unlike many European countries of similar economic, social, scientific, and political advancement, there is virtually no regulation of preimplantation genetic testing in the United States. This Note will explore preimplantation genetic testing and demonstrate that potential parents in the United States have a right to conduct said testing under the umbrella of the fundamental right to privacy. This Note will demonstrate the need for the regulation for preimplantation genetic testing that will comply with the Undue Burden Test set out in Planned Parenthood v. Casey, while acknowledging and supporting the fundamental right of potential parents to conduct testing. This Note will also address how potential regulations, or lack thereof, of preimplantation genetic testing may affect disabled people and their rights.

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Since the Nation’s founding, there has been an ongoing battle for the clarification and expansion—or restriction—of Constitutional rights in the United States. One of the rights at the very heart of
This battle is the right to privacy—a right that the Supreme Court has defined very broadly. However, changing political and social environments can and likely will alter the way these rights are treated in the courts. This Note will explore the right to privacy, and whether it should encompass the right to have preimplantation procedures performed on embryos during family planning, focusing specifically on preimplantation genetic testing.

There are two main forms of preimplantation genetic testing: preimplantation genetic screening (PGS) and preimplantation genetic diagnosis (PGD). There are currently no limitations or regulations on either of these procedures in the United States. Similar to the decisions in Roe and Casey, the right to privacy encompasses the right of potential parents to have PGS and/or PGD performed when attempting to conceive, and they should be protected by the fundamental right to procreate and raise children. However, modern opposition to the Court’s decision in Roe threatens this fundamental right to privacy in family planning. Additionally, the lack of regulations in the United States on PGD and PGS arguably distinguishes this testing from the Court’s precedential decisions. In previous landmark Supreme Court decisions, the Court has established that regulations on certain health practices are appropriate when states hold a compelling interest in the health of their residents and in protecting prenatal life. In Roe v. Wade, the Court expanded the fundamental right to privacy to cover the right to obtain a legal abortion, advancing a greater right to privacy in family planning and reproduction. In Planned Parenthood v. Casey, the Court explored the states’ interest in potential life, and also created the Undue Burden Test for regulations on fundamental rights, including the right to obtain an abortion.

1. See Griswold v. Connecticut, 381 U.S. 479, 479–86 (1965) (establishing that the fundamental right to privacy is broad).
5. See, e.g., Roe, 410 U.S. at 114; Planned Parenthood, 505 U.S. at 837 (determining that regulations on certain procedures are appropriate when a legitimate government interest is present).
6. Roe, 410 U.S. at 114 (holding that restrictions upon abortion services are appropriate when there is a compelling government interest involved).
7. Id.
8. See Planned Parenthood, 505 U.S. at 837.
In Part I of this Note, I will provide a background of PGD and PGS in both Europe and the United States. I will detail the ethical implications associated with both procedures, as well as explore the current regulations, or lack thereof, governing PGD and PGS in the United States. In Part II, I will provide a background and analysis of both Roe v. Wade and Planned Parenthood v. Casey—perhaps the Supreme Court’s most detailed discussions involving the intersection between the right to privacy and the states’ right to regulate and, therefore, the most relevant to the issue of PGT. Finally, in Part III, I will apply the Court’s reasoning and holdings in Roe and in Casey, to establish an analytical framework for arguing why people in the United States have a Constitutional right to have PGD and PGS, procedures performed as part of family planning. I will explore what might happen to these rights if Roe v. Wade is eventually overturned and conclude with potential regulations that states might implement as PGT becomes more widely used.

I. OVERVIEW OF PREIMPLANTATION GENETIC DIAGNOSIS AND SCREENING

Preimplantation genetic testing (PGT) is often used as an umbrella term for all preimplantation genetic testing including PGS and PGD, however there are key differences in the different types of genetic screening of embryos. Both are used commonly in concurrence with in vitro fertilization (IVF).

IVF refers to the procedures used to help with infertility or to prevent certain hereditary conditions in children of potential parents. Potential parents often turn to IVF in order to conceive for a number of reasons; for example, potential parents may turn to IVF if a woman has endometriosis, a condition that makes it difficult to become pregnant naturally, or in order to preserve future fertility by storing eggs before undergoing cancer treatment. Parents may
also turn to IVF treatment due to male infertility, as well. In the United States, use of IVF or other reproductive technologies is very common; approximately 55,000 women give birth with the help of reproductive technologies each year. About one third of Americans have either used fertility treatments or know someone else who has. Mature eggs are retrieved from a patient’s ovaries, and the eggs are then fertilized artificially creating embryos. The embryos can then undergo tests or be implanted into a potential parent or surrogate’s uterus. It is common for unused embryos to either be stored for future use or destroyed if left unused. While IVF is one of, if not the most, effective form of assisted reproduction, it can be an extremely costly procedure in terms of both time and money. The average IVF cycle takes around three weeks each time, but can take much longer.

A. Preimplantation Genetic Screening & Preimplantation Genetic Diagnosis

1. Preimplantation Genetic Screening

PGS does not look for any specific condition; it is used primarily to look for a “normal chromosome number.” A normal chromosome number indicates that there is no genetic chromosomal abnormality in the fetus. Moreover, there are a number of ethical implications that have been related to PGS. PGS may provide the opportunity

13. Sahar M. Stephens, Daniel M. Arnett & Randall B. Meacham, The Use of In Vitro Fertilization in the Management of Male Infertility: What the Urologist Needs to Know, 15 REV. UROL. 154, 154 (2013) (explaining that infertility affects anywhere from one in 10 to one in five couples; “male factor” infertility is estimated to make up about two-thirds of all cases of infertility).
15. Id. (demonstrating how common and widespread the use of reproductive assistance tools is in the United States).
16. In vitro fertilization (IVF), supra note 11 (describing the medical and scientific process of IVF).
17. Id.
18. Id.
19. Id.
20. Id.
21. PGD and IVF—Preimplantation Genetic Diagnosis and In Vitro Fertilization, supra note 9.
23. Id.
24. Wybo Dondorp & Guido de Wert, Refining the Ethics of Preimplantation Genetic Diagnosis: A Plea for Contextualized Proportionality, 33 BIOETHICS 294, 295 (2019) (defining PGD as “ethically sensitive” and comparing it to selective abortion).
for potential parents to know and select the gender of fertilized embryos for implantation, which may potentially “open the doors to sex selection.”25 However, many European countries have at least some form of regulation or restriction on PGD.26 Italy, for example, used to require that no unused embryos be destroyed during IVF; patients are required to limit embryos created during IVF to three.27 It is also required that doctors transfer all viable embryos to the patient’s uterus in order to avoid unnecessary storage or discarded embryos.28 Italy had also created an outright ban on PGD, even for potential parents who carry hereditary conditions that they may not want to pass onto any of their own biological children.29 Both of these restrictions have since been lifted, however PGD may only be used for prevention of a “sufficiently serious disease.”30

France, on the other hand, allows for PGD but only if performed by a “specially certified fertility specialist” and only to weed out a serious and incurable disease in the embryo.31 In the United Kingdom, PGD regulations are more specific about what constitutes a valid reason to undergo PGD.32 For example, doctors are required to submit an application on behalf of their patient to the Human Fertilization and Embryology Authority (the HFEA).33 The HFEA gives out licenses for PGD only if there is a significant risk of “a serious physical or mental disability,” “a serious illness,” or “any other serious medical condition” with the embryo.34

25. Jason Christopher Roberts, Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical and Legal Dilemmas, 2002 DUKE L. & TECH. J. 0012 (2002), https://dltr.law.duke.edu/2002/07/23/customizing-conception-a-survey-of-preimplantation-genetic-diagnosis-and-the-resulting-social-ethical-and-legal-dilemmas [https://perma.cc/C95E-5ZSL]. “Sex selection” refers to the process of providing the opportunity to screen fertilized embryos for a preferred biological sex. Id. It is common in some countries, such as India and China, to opt for “selective abortion” in order to prevent having a child of an unpreferred biological sex. Id. In these same countries, whether for purposes involving lineage or economic opportunity, many families find it preferable to only bear male children, and thus rates of female infanticide and selective abortion of female fetuses are common. Id. Very few organizations in the United States support using PGD for sex selection, citing the belief that it is not unethical to prefer a child of a certain biological sex, whether it be for any reason ranging from want of a specific type of companionship or wanting a child of opposite sex than one’s existing child or children. Id.

26. Michelle J. Bayefsky, Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and Its Implications for Reproductive Tourism, 3 REPROD. BIO MED. & SOC’Y ONLINE 41, 41–45 (2016).

27. Id.
28. Id.
29. Id.
30. Id.
31. Id.
33. Id.
34. Id.
There are organizations around the world who advocate for the right to select certain traits or the gender of an embryo. A sample of the arguments given for “social sexing” offered by the European Society of Human Reproduction and Embryology (the ESHRE) includes the right to “procreative choice,” “self-regulation of countries,” and that not selecting embryos of an “unwanted sex” is a “preferred alternative to abortion.” The ESHRE focuses on promoting interest in reproductive biology and medicine while also promoting safety in these reproductive procedures.

Additionally, PGS can be used to select certain traits (or a lack thereof), such as deafness. Some individuals in the Deaf community have expressed concern that “hearing” parents, or parents who are not deaf, carry the misconception that Deaf children cannot live happy, productive lives conditional on the ability to hear. Hearing people continue to think of deafness as a negative affliction—something that would prefer to be avoided if possible—while many in the Deaf community view being deaf as a positive experience, something not to be altered. In fact, it is actually becoming more common for parents to refuse cochlear implants for their Deaf children. In a study conducted by the Genetics and Public Policy Center at Johns Hopkins University, it has been suggested that some individuals use PGS to “select genetic characteristics beyond those linked to severe or deadly disease.” A great underlying concern held by opponents of PGS is that its use may result in a rise in popularity of “designer

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35. Roberts, supra note 25.
36. Id.
39. Allegra Ringo, Understanding Deafness: Not Everyone Wants to be ‘Fixed’, ATLANTIC (Aug. 9, 2013), https://www.theatlantic.com/health/archive/2013/08/understanding-deafness-not-everyone-wants-to-be-fixed/278527 [https://perma.cc/5DTK-GXWF] (“Hearing people” refers to individuals who are not deaf or hard of hearing. Lowercase “deaf” is used to refer to the condition of deafness, while uppercase “Deaf” is used to refer to a particular group of deaf people).
40. Brianna J. Daisy, Deaf People in a Hearing World: A Qualitative Study of Cultural Identity Issues 17 (2008) (Master’s Thesis, University of New Hampshire) (on file with the University of New Hampshire Scholars’ Repository) (identifying certain aspects of Deaf culture, and how it varies compared to hearing culture).
41. Rachel Cooper, Can it Be a Good Thing to Be Deaf?, 32 J. MED. & PHIL. 563, 564 (2007) (“Deaf parents have refused cochlear implants for their children, and others have refused genetic testing designed to enable the detection and abortion of deaf fetuses. There have also been cases where Deaf couples have purposefully conceived deaf babies, in the belief that it is good to be deaf.”).
42. Baruch, supra note 3, at 246.
babies.” While designer babies may sound like something out of a science-fiction novel, the term refers to children who have been genetically engineered or altered to have—or not have—specific traits. For example, potential parents would essentially be able to select their offspring’s eye color, height, or degree of athletic ability. Just one of the issues arising with designer babies may be the creation of a social rift between those who can afford these procedures and those who cannot. It may also create a similar rift between those who might be considered “enhanced” and those considered “unenhanced” depending on the traits that potential parents would be able to select. In a 2016 study conducted by STAT and Harvard T.H. Chan School of Public Health, 65% of Americans surveyed answered that it should not be legal to change the genes of embryos in order to reduce the risk that they might develop serious diseases once born. In the same study, 83% of those surveyed answered that altering the genes of embryos in order to improve intelligence levels or certain physical characteristics should not be legal. One of the major benefits of PDS and PGD however, is that neither involve changing any genes.

2. Preimplantation Genetic Diagnosis

PGD is used primarily to diagnose specific genetic conditions in embryos such as cystic fibrosis or sickle cell anemia. Compared to PGS, there is typically a lower cost associated with conducting PGD. However, like PGS, there have been a number of ethical implications associated with conducting PGD. PGD requires the creation of fertilized embryos that will ultimately not be used by potential parents.

43. Id.
45. Id. (citing only a handful of the many characteristics that potential parents would be able to hand-pick for the embryo).
46. Id.
47. Id.
49. Id.
51. Ly, supra note 44.
52. PGD vs. PGS, supra note 10 (explaining that PGD involves the cost of a cell biopsy, as well as the cost of the genetic testing. This can range in total from $2,500.00 to $3,500.00 and varies depending on how many embryos will be tested. PGS, on the other hand, may cost between $5,000.00 and $6,000.00).
53. See Bayefsky, supra note 38, at 1163.
This has been compared to abortion, and has been cited as “disregard[ing] or at least devalu[ing] the sanctity of life.” There is also a concern that by using selective implantation, genetic diversity could be threatened and potentially eliminated altogether. Low levels of genetic diversity are accompanied with an increased risk for extinction. Finally, similarly to PGS, many advocates for people with disabilities have viewed genetic testing and embryo selection as a “message that people with disabilities are less highly valued than those without” when potential parents look to select embryos who do not show signs of certain disabilities or conditions.

B. Current Status of PGD and PGS in the United States

Although IVF clinics in the United States are required to report annual pregnancy success rates to the Centers for Disease Control and Prevention (CDC) in accordance with the 1992 Fertility Clinic Success Rate and Certification Act (FCSRCA), there are currently no requirements for IVF clinics to report data relating to PGD according to the CDC. On a similar note, Pennsylvania and Illinois have passed regulation to limit abortions being performed for specific reasons such as sex selection, but these regulations have not been strictly enforced.

Although there are no regulations, several professional organizations in the United States have issued opinions on whether PGD and PGS should be allowed. Both the American Society for Reproductive Medicine (the ASRM) and The American Congress of Obstetricians and Gynecologists (the ACOG) have issued opinions condemning the use of genetic testing for sex selection.

In one 2017 study, approximately 72.7% of fertility clinics in the United States offer sex selection to prospective parents. Approximately 83.5% of those clinics offer sex selection to “couples without

55. See id.
56. See Low genetic variation, UNIV. CAL. MUSEUM PALEONTOLOGY, https://evolution.berkeley.edu/the-relevance-of-evolution/conservation/low-genetic-variation [https://perma.cc/8GR7-H244] (last visited Apr. 7, 2022) (explaining that if a certain genetic variation is not present in a population, and the population is introduced to a new disease, there is an increased likelihood that the population will be eradicated by that disease).
57. Lagay, supra note 54, at 266.
58. Baruch, supra note 3, at 262.
59. Id.
60. Bayefsky, supra note 26, at 43.
61. Id. (describing the ASRM statement discouraging non-medical sex selection, and now takes a neutral position and the ACOG’s statement discourages any sex selection by assistive reproductive tools).
62. Bayefsky, supra note 38, at 1160.
infertility,” meaning that the couple would undergo IVF procedures solely to select the sex of their child.63 Public opinion differs on support for sex and trait selection.64 In a 2015 United States study of a sample of 1,006 individuals, it was found that 21.1% of respondents were in favor of using PGD for sex selection.65 From the same sample, however, only 14.6% and 18.9% were in favor of PGD use for selecting physical traits and personality traits, respectively.66 It has been suggested that the leading non-medical use of PGD in the United States is for sex selection.67

While the United States is behind its European counterparts in the regulation of PGD and PGS, there may be some underlying reasons for these differences.68 Unlike Europe, the United States lacks a government-sponsored healthcare system.69 Italy, France and the United Kingdom, for example, all have healthcare systems that are either fully or almost fully funded through their respective governments.70 Both France and the United Kingdom actually have government-funded insurance for a certain number of IVF cycles for women who satisfy certain requirements.71 Italy, on the other hand, has a certain amount of funds allocated for assisted reproduction.72 This is in stark contrast to the United States, where most people obtain private insurance and American government-funded healthcare “does not cover” any “advanced fertility treatment,” including IVF and PGD.73

II. ROE V. WADE AND PLANNED PARENTHOOD V. CASEY

A. Roe v. Wade

There is no case that pertains more to the right to choose to have children than Roe v. Wade. In the circumstances surrounding this landmark decision, the Texas Penal Code restricted almost all

63. Id.
65. Id.
66. Id.
67. Id. at 666.
68. See Bayefsky, supra note 26, at 43.
70. See Bayefsky, supra note 26, at 44.
71. Id.
72. Id.
73. Id.
Abortions, allowing the procedure only in cases involving the potential death of the mother. In its holding, the Court outlined the trimester framework: any State counter-interest to abortion is outweighed by women’s privacy interest in the first trimester, and there may be no restrictions to abortion during that time. At approximately the end of the first trimester is when a state’s interest in prenatal life becomes compelling, and at that point states may impose restrictions or even complete bans on abortion unless a mother’s life is in danger. The Court employed strict scrutiny review because the fundamental right to privacy was involved. The Court required that states have a compelling interest in order to implement restrictions within the trimester framework.

B. Planned Parenthood v. Casey

In Planned Parenthood v. Casey, a Pennsylvania law implemented various restrictions on women looking to obtain abortions, including informed consent, a 24-hour waiting period, spousal notification for married women, and a requirement that minors receive informed consent from at least one parent before obtaining a legal abortion. Unlike the holding in Roe, the Court determined that strict scrutiny review used previously was not appropriate, and instead implemented the Undue Burden Test.

The Undue Burden Test states that a regulation places an undue burden on a woman’s right to obtain an abortion when the purpose of that regulation is to place a substantial obstacle in that woman’s path to obtain an abortion. Regulations that could potentially constitute an obstacle restrict abortions before a fetus has attained viability. Though the Court continued to recognize “the right of the individual . . . to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person[—such]
as the decision whether to bear or beget a child\textsuperscript{83}—the Court also concluded that states have a legitimate interest in protecting prenatal life from the beginning of pregnancy.\textsuperscript{84} The trimester framework was abandoned, with the intent of protecting “the central right recognized by Roe v. Wade while at the same time accommodating the State’s profound interest in potential life.”\textsuperscript{85} The Court’s decision in Casey increased government control over women’s and their partners’ right to privacy in family planning, and utilized the “undue burden” standard.\textsuperscript{86}

III. THE RIGHT TO CONDUCT PGD AND PGS

A. Application of Roe and Casey

Although the main issue at hand in Roe v. Wade was the right to obtain an abortion, the core right established in Roe was a broader right to privacy.\textsuperscript{87} On the other hand, the primary State interest that the Court focused on in Planned Parenthood v. Casey was the interest in “protecting potential life.”\textsuperscript{88} Because PGT falls under the right to privacy and deals largely, if not exclusively, with what many would consider “potential life,” these are the two most important cases relating to the right to conduct PGT and the states’ interest in regulating the procedure. Allowing for the use of PGT in family planning and reproduction, while also allowing for the reasonable regulation of it in accordance with a state interest, follows the same logic that the Court used in allowing for access to abortion while also permitting State regulation of the procedure.

Because the Court in Casey abandoned the trimester framework set out in Roe, citing the undermining of the State interest in regulating abortion, it would be unreasonable to think of prohibiting State regulation of a similarly controversial procedure simply because it takes place before a “formal” pregnancy.\textsuperscript{89} The Court concluded that the moment when a fetus attains viability is not the threshold at which State interest takes place.\textsuperscript{90} Similarly, the point in time where a fetus is viable would not be the threshold in the

\textsuperscript{83} Id. at 896.
\textsuperscript{84} See id. at 873.
\textsuperscript{85} Casey, 505 U.S. at 878.
\textsuperscript{86} See discussion, supra Section I.B.
\textsuperscript{88} Casey, 505 U.S. at 837.
\textsuperscript{89} See id.
\textsuperscript{90} See id.
regulation of preimplantation testing. However, following the Court’s rationale in \textit{Casey}, any regulation would need to satisfy the “undue burden” standard.\footnote{See \textit{id}.} Though the Undue Burden Test has historically been applied to cases involving abortion, \textit{Casey} did not state that the test must be exclusively used for abortion.\footnote{Id. at 877.} Because of the similarities between abortion and PGT, it is the appropriate test to use when drafting and implementing regulations on PGT in the United States.

\textbf{B. Implications of Overturning \textit{Roe} v. Wade}

Ginsburg’s dying wish, as stated to her granddaughter, to not be “replaced until a new president is installed.” 98

Amy Coney Barrett is a staunch Catholic and has been associated with the People of Praise, a Christian group from Indiana that encourages narrow gender-roles and utilizes a male-dominated hierarchy. 99 This male-dominated hierarchy is also encouraged to be implemented in family life for the members of the group, and some have suggested that the group promotes women to submit themselves to men. 100 While the group declines to specify whether Barrett is an actual member of the group, the group removed any edition of their magazine that included her name and photo from their website. 101 Merely being associated with a group that, by today’s standards, holds archaic views of both private and public life, suggests that Barrett’s conservative roots likely influence her decisions in everyday life and potentially her decisions as a Supreme Court Justice. Barrett has, in the past, also advocated for overturning the Roe decision, having signed a 2006 letter referring to the right to obtain an abortion as “barbaric.” 102 The same letter also condemned the discarding of unused embryos during IVF procedures, claiming that the practice should be criminalized. 103

In one of the closest Senate votes in United States history, Barrett was confirmed to the Supreme Court by a 52–48 vote on October 26, 2020. 104 Barrett’s appointment has created a 6–3 conservative-liberal division in the Court. 105 Despite that Barrett has vowed to act independently of her own political views, there are still ever-present, and likely merited in some cases, concerns that personal bias may make its way into her and other justices’ decisions. 106

98. Id.
100. Id. (suggesting that Coney Barrett was at one point a member of this organization).
101. Id.
103. Id.
105. Id. (giving information about the current ratio of political beliefs held by the Justices within the Supreme Court).
106. See id.
Prior to fall 2020, a majority of Americans viewed the Supreme Court as “middle of the road.” Now that Barrett has been appointed to the Court, there is a widely held apprehension that the Court will shift to one of strongly, far-right conservative ideology with then-President Donald Trump having selected three Supreme Court Justices at that point. This ideological shift could easily remain in place for several decades to come, with the longest term served in history being over thirty-six years by William O. Douglas.

While the Supreme Court may eventually overturn Roe v. Wade, state legislation can still protect the reproductive rights of residents. In many states, the access to abortion and other controversial reproductive tools will likely remain protected and unchanged. Partisan division will likely have the biggest impact on the equality of access to abortion or other controversial reproductive services across the country, with most states that face a probable ban having a history of voting for conservative lawmakers.

If left to the states, a number of jurisdictions may opt to severely limit the reproductive freedom of their residents. Twenty-one states currently have laws that could potentially be used to restrict the legal status of abortion. Twelve states currently have laws that will be triggered if Roe v. Wade is overturned, which either ban “all or nearly all abortions”; seven other states have laws that “express the intent to restrict” the right to obtain an abortion “to the maximum extent” in the event that Roe v. Wade is overturned.

This could easily extend to the restriction of other forms of reproductive freedoms, such as IVF and PGT, because many opponents of abortion will likely cite similar reasons for opposing these.

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108. Id.

109. Peter Aitken, How long each Supreme Court Justice has served on the bench, and how long it took to confirm them, FOX NEWS (Sept. 19, 2020), https://www.foxnews.com/politics/supreme-court-justice-served-how-long-to-confirm [https://perma.cc/AP6Q-VF7J].


113. Id.
reproductive tools. Some of the reasons cited by “anti-choice” (also commonly referred to as “pro-life”) activists include the belief that life begins at conception, and that a fertilized embryo is entitled to the same rights and consideration as any human that has already been born. Because both IVF and PGT often involve discarding unused embryos, it is probable that these reproductive tools will face similar backlash and restrictions to abortion if Roe v. Wade is overturned. However, despite anti-abortion advocates potentially raising similar concerns as they would with abortion with pre-implantation genetic screening, PGS could become an alternative to abortion in many cases. Individuals who know they run the risk of having an abnormal pregnancy—whether it be for knowledge of their own genetic health conditions or otherwise—may otherwise turn to abortion to stop their pregnancy with a fetus found to have certain conditions. As an alternative option to abortion, preimplantation screening has the potential to give some peace of mind in knowing that genetic conditions can be screened out.

Many European countries have seen recent conservative political movements, which have resulted in increased right-leaning legislation, including restrictions on abortion services. Poland in particular has recently seen a great deal of social and political unrest because of a tightening of abortion laws. Poland, a country in which


116. See Erik Aarden, Ine Van Hoyweghen, Rein Vos & Klasien Horstman, Providing preimplantation genetic diagnosis in the United Kingdom, The Netherlands and Germany: a comparative in-depth analysis of health-care access, 24 HUM. REPROD. 1542, 1543–44 (2009) (suggesting that individuals who want children may be able to use preimplantation testing to solve issues that would otherwise cause them to seek an abortion).

117. See id. at 1545.


almost 90% of residents identify as Catholic, has introduced an almost-complete ban on all abortion services, even in the case of fetal abnormalities, which, along with cases of rape, incest, and those pregnancies that are a danger to the mother’s life, were previously protected by regulation.

Additionally, because of the bans on preimplantation testing and other related reproductive services, it is actually not uncommon for Europeans to come to the United States to obtain preimplantation genetic testing services. Because there is no hope of obtaining these services in their home country, many individuals in need of reproductive procedures and assistance seek care elsewhere. This phenomenon is known as “reproductive tourism,” which carries with it its own legal, ethical, and health considerations as there are currently no regulations on preimplantation testing in the United States.

Despite not yet being regulated, PGT and PGS will likely come under fire if Roe v. Wade is undermined or overturned. One way to help advocate for protection even if the Roe decision is overturned is to be active in presidential elections, but perhaps even more importantly, to be active in local elections. It is important to vote because although just one individual vote may not have a large impact in every election, voters coming together to make a change can have sizable effects on socio-political climate. Many elected officials, however, win by only a small margin, where every vote counts tremendously. For example, only 537 votes ended up deciding the


123. Id.


127. Id.
outcome of the 2000 Presidential Election in a vote recount.\textsuperscript{128} Local elections are particularly important because of the immediacy of the impact they have on everyday life.\textsuperscript{129} It can take years for any change in laws and regulations at the federal level.\textsuperscript{130} Local and state elections have a much more immediate and frequent impact on the quality of life for residents.\textsuperscript{131} Voter turnout is also typically lower in local and state elections than it is for national elections.\textsuperscript{132} Individual votes, therefore, count that much more in these smaller scale elections.\textsuperscript{133} Nothing is as important to reproductive rights as making an effort to vote for lawmakers who support the protection of abortion and other reproductive tools.\textsuperscript{134}

C. Suggested Implementation of Regulations

The right to choose to have an abortion, to procreate, and to private family planning is synonymous with the right for prospective parents to choose to have a child on their own terms. Because there are currently no regulations or legislation suggesting otherwise, the umbrella of the right to privacy includes PGD and PGS procedures, which have become increasingly important parts of family planning.\textsuperscript{135} Because there is a fundamental right related to PGS and PGD as well as a compelling state interest in protecting prenatal life,\textsuperscript{136} there should be an implementation of some regulations—such as a requirement for informed consent or a waiting period—in order to further that compelling state interest, while also protecting the rights of prospective parents.

The right to conduct preimplantation genetic testing is covered by the umbrella of the fundamental right to privacy, and therefore any regulation of the procedure would need to be justified by a compelling state interest.\textsuperscript{137} The regulations would also need to satisfy

\textsuperscript{128} Id.
\textsuperscript{130} Id.
\textsuperscript{131} Id.
\textsuperscript{133} Id.
\textsuperscript{134} Keep on Marching, supra note 125 (describing various ways that U.S. citizens can impact the protection of reproductive rights).
\textsuperscript{135} Baruch, supra note 3.
the “undue burden” standard created in Planned Parenthood v. Casey.\textsuperscript{138} It is well-established that states have an interest in protecting prenatal life.\textsuperscript{139} Many reproductive assistance tools involve the discarding of unused embryos.\textsuperscript{140} As embryos would likely be considered prenatal life, any regulation could potentially impact not only preimplantation genetic testing but also IVF and any other reproductive tool. It is important to balance the right to have reproductive care and tools available with the government’s interest in protecting prenatal life.

The reasoning behind certain regulations however, no matter how compelling they may seem, could create a multitude of issues, particularly if following a slippery slope argument. For example, if a state’s compelling interest in protecting prenatal life leads to the criminalization of IVF or other assisted reproduction because embryos may either be left unused or discarded, who is to say that eventually, a woman’s unused eggs or a man’s unused sperm violates the state’s compelling interest? Unused eggs within the body or sperm outside of the body not being used to create children could be considered potential prenatal life. If this were the case, it would create a serious concern for bodily autonomy. Some regulations could even infringe upon the right to choose whether to have a family in the first place if unused eggs or sperm were deemed potential life. This could quickly create a slippery slope into the widespread termination of previously fundamental rights. It is difficult to discern between a threshold of too much regulation and one of too little.

Similar to the Court’s decision and recommendations in Planned Parenthood, one regulation that might be implemented is a waiting period of a certain duration of time before implanting selected embryos, therefore waiting to discard embryos that were not selected for non-medical reasons such as sex or trait selection. Because IVF is time sensitive in many cases due to (1) a decline in fertility in both men and women with age; and (2) carefully scheduled medications and doctors’ appointments, any waiting period should not be extensive or place an undue burden on prospective parents.\textsuperscript{141} It is important to balance the right to privacy and the right to make

\begin{flushleft}
\textsuperscript{138} Id. at 878.
\textsuperscript{139} Id. at 871.
\textsuperscript{140} Simopoulou et al., supra note 115, at 2448 (providing information that IVF and PGS involve the discarding of unused embryos or embryos found to have genetic abnormalities and in PGS’s case, unwanted hereditary conditions).
\end{flushleft}
autonomous decisions with the government’s interest in prenatal life and safe medical procedures.

There should also be a requirement that prospective parents give informed consent for the risks of the procedure of screening or diagnosis. Similar to an informed consent requirement for abortion, informed consent in regard to PGS would involve non-biased counseling on the different testing options, as well as counseling for options apart from preimplantation testing.\textsuperscript{142} Because both PGS and PGD require IVF in order to be performed, it is important that prospective parents understand how IVF works, as well as how the testing will be conducted.\textsuperscript{143} With this comes the risk of harming embryos or the receipt of false negatives on tests for certain conditions, resulting in the disposal of healthy embryos.\textsuperscript{144} Additionally, any unused embryos, regardless of health conditions or damage, are typically discarded.\textsuperscript{145} Finally, PGS does not test for all possible genetic conditions, and the procedure can be costly, coming in between $5,000 and $6,000 each time it is done.\textsuperscript{146} These are just some of the factors that potential parents looking to conduct PGT on their embryos will need to consider and be informed of before the procedure. Introducing the requirement to give informed consent will likely pass the Undue Burden Test laid out in \textit{Planned Parenthood} as it is merely a step to ensure that potential parents fully understand the procedure they are undertaking and does not place any substantial obstacle in their path to have preimplantation testing done.\textsuperscript{147} It would, however, be difficult to ensure a particular level of understanding for all potential parents.

\section*{IV. Implications of Regulating PGD and PGS}

While there is a clear need for some kind of regulation for preimplantation genetic screening in the United States, regulations

\begin{itemize}
\item \textsuperscript{143} \textit{In vitro fertilization (IVF)}, supra note 11.
\item \textsuperscript{145} Sheryl de Lacey, Parent Identity and ‘Virtual’ Children: Why Patients Discard Rather Than Donate Unused Embryos, 20 HUM. REPROD. 1661, 1661 (2010).
\item \textsuperscript{146} Emily Mounts, Top 5 Myths About Preimplantation Genetic Screening (PGS), ORM GENOMICS, https://ormgenomics.com/2018/05/24/top-5-myths-pgs [https://perma.cc/44ZT-D5KW] (last visited Apr. 7, 2022) (stating that PGS does not test for all possible hereditary and congenital conditions); \textit{PGD v. PGS}, supra note 10 (explaining the monetary costs associated with conducting PGS).
\item \textsuperscript{147} \textit{Planned Parenthood v. Casey}, 505 U.S. 833, 887 (1992) (“The informed consent requirement is not an undue burden on that [constitutional right to abortion on demand].”).
\end{itemize}
and restrictions do not come without risk. Not only are there concerns for the future impact that certain regulations might have on reproductive rights, but there are other groups within the United States that need to be considered when choosing to allow and regulate PGT. While there is undoubtedly a state interest in prenatal life, there is also a governmental interest in the general welfare of the residents of each respective state. 148 Logically, this interest would extend to individuals living within the state, including those living with disabilities. Approximately 61 million adults in the United States live with a disability, whether it be cognitive or physical. 149 This means that approximately 26%, or approximately one in every four, of American adults are currently living with some kind of disability. 150 Because those with disabilities make up a unequivocally large portion of the U.S. population, any regulation on PGT will need to strike a balance between the rights of potential parents and the protection of those living with disabilities for reasons discussed below. Without this balance, quality of life—or even the ability and opportunity to live at all—for many will be threatened.

If it becomes a trend to discard or select embryos based on the presence, or lack thereof, of a genetic abnormality or hereditary condition causing disability, it could influence both the social and political views of those currently living with disabilities, likely in a negative way. Despite major developments in recent history for the rights of disabled people in the United States, such as the introduction of the Americans With Disabilities Act (ADA), there is a modern movement for the reduction of rights for the disabled. 151 For example, the recent push to repeal the Affordable Care Act aims to eliminate Medicaid. 152 Over 10 million people in the United States currently qualify for Medicaid due to a disability. 153 The elimination of Medicaid and other related services would effectively wipe out the funding for many disabled people’s medical care—medical care

150. Id.
152. Id.
which many could otherwise not afford. While these pushbacks have largely been orchestrated almost exclusively by particular political groups, if anti-disability rights activists garnered more widespread support, progressive legislature could be blocked, and old legislature could be repealed. Disabled people are one of the last marginalized groups whose equal rights have begun to be recognized. Not only has so much been done in the realm of disability rights activism, such as education and healthcare laws, but there is still quite a bit of work to be done, both in the United States and on a global scale. If the general public begins to develop a negative view of those with disabilities, however, years of advocacy and progress for the rights of the disabled will be undone. This is not to mention the steps that still need to be taken in virtually every area of everyday life, from employment to personal biases. Because state governments have an interest in the well-being of all of their residents, lawmakers and voters will need to consider the negative impact that any regulations or lack of regulation may have on significant portions of the population.

CONCLUSION

The changing political and social climate in the United States creates the frightening possibility that some rights, such as control over private family planning, previously held as fundamental, will no longer be protected. The push seen under the Trump Administration to overturn Roe v. Wade is a prime example of the threat on reproductive rights. If certain lawmakers and members of the judicial branch are successful in their attempts to overturn Roe v. Wade, the right to these fundamental rights could be threatened, or even eliminated entirely. While the election of Joe Biden in late 2020 may shed a ray of light on the fight for the conservation of

154. Pettinicchio, supra note 151.
155. Id.
157. Id. (explaining that many countries, including the United States, lack basic tools that would benefit disabled people in everyday life such as accessible transportation and stairs. Additionally, the right to quality education at all academic levels for disabled people is only constitutionally guaranteed in approximately 28% of countries worldwide.).
158. Pettinicchio, supra note 151 (The United States has already taken some steps backwards in the fight for equal rights for disabled people. For example, the Department of Justice no longer enforces website accessibility requirements; the Trump Administration also urged the Supreme Court to deny a case involving accessibility and vending machines).
159. Brink, supra note 156.
reproductive rights, the Trump Administration will certainly have a lasting impact through legislation, Supreme Court nominations, and a strong social influence.

Following the analysis of both *Roe v. Wade* and *Planned Parenthood v. Casey*, there is a fundamental right to choose the “if, when, and how” when it comes to sexual reproduction. Even with regulations, however, not only are there questions about the future of reproductive freedom, but also the possibility of negative fallout that such regulations could have for certain marginalized groups. If the use of PGT becomes widespread, some groups such as those with disabilities could be negatively impacted. Because of this, there are a wide range of considerations to be made when considering the creation and implementation of regulations for PGT. Ultimately, however, there is a fundamental right to make decisions involving one’s own reproductive present and future.

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