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INTRODUCTION

In 2005, advocates and health professionals across the country filed amicus briefs in *Gonzales v. Carhart*, a case before the Supreme

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Court of the United States.[1] The case considered the federal ban of a specific abortion procedure popularly known as "partial birth abortion" and clinically described as intact dilation and evacuation (intact D&E). The procedure is performed in the second or third trimester of pregnancy and received its popular name because the fetus is kept intact as it is extracted through the birth canal. One amicus brief retold the experiences of women who had intact D&Es, banned by the federal law. In almost all of the brief's examples, women decided to end their pregnancies because prenatal testing revealed severe genetic disorders.

For example, Claudia Crown Ades, following consultation with her obstetrician, a genetic counselor and perinatologist, ended her seven-month pregnancy after learning the baby she carried would be born with a non-functional brain and a malformed heart.[2] The brief quoted the testimony of Ms. Ades's husband before a congressional hearing: "I don't know what I would have done without this medical option . . . I knew, after all the discussions, deliberations and questioning that both Claudia and I did, that [intact D&E] was the safest, most humane procedure available to our family. For that, I am grateful."[3]

The Ades' experience illustrates the difficult decision-making when confronted with information about a serious genetic condition of a potential child. It also highlights a popularly accepted reason for abortion—genetic disorder or fetal malformation.[4] Indeed, one of the primary rationales for legalizing abortion in the United States was the reason of fetal anomaly.[5] Since *Roe v. Wade,* women who elect prenatal genetic screening and testing have had the legal option to terminate pregnancies for conditions like the chromosomal deletion at issue for Claudia Crown Ades. Many women will opt to raise children diagnosed with a genetic disorder or will forgo testing because they would not elect abortion in any case. Yet for those who would choose abor-

1. Gonzales v. Carhart, 550 U.S. 124, 124 (2007). *See* discussion *infra* Parts II.D, III (discussing *Gonzalez v. Carhart* case).

2. Brief for the National Women's Law Center et al. as Amici Curiae Supporting Respondent at 10, Gonzales v. Carhart, 550 U.S. 124 (2007) (No. 05-1382).

3. *Id.*

4. Polls in 2007 suggest that seventy percent of Americans believe abortion should be available for reasons of fetal malformation or genetic disorder. Amy Harmon, *Genetic Testing + Abortion = ???*, N.Y. TIMES, May 13, 2007, at 1.

5. Reva B. Siegel, Roe's *Roots: The Women's Rights Claims that Engendered* Roe, 90 B.U. L. REV. 1875, 1879 (2011) (citing the 1962 proposals of the American Law Institute that permit abortion, upon the review of two physicians, for reason of rape or incest, mother's physical or mental health, or fetal anomaly).

tion, the ability to screen and to test prenatally for genetic anomalies is expanding while abortion access, especially near or after viability, is contracting.

In the next two decades, researchers predict that a "simple," maternal blood test can yield fetal DNA. Coupled with gene sequencing, parents will be able to know much more about a fetus's genetic make-up much earlier in pregnancy.[6] Moreover, as testing and sequencing technology evolve, researchers predict that prenatal genetic testing will become more cost-effective, more manageable, more accurate, and, thus, more routine.[7]

At the same time prenatal genetic testing is expanding, women's ability to gain access to abortion services is contracting. Federal and state laws directly and indirectly restrict abortion in the United States, and states pass new anti-abortion legislation every year. In 2011, state legislatures passed eighty laws, double the number passed only six years earlier, restricting abortion in a variety of ways, such as bans on all terminations after twenty weeks of gestation and onerous regulations of clinic facilities.[8]

The Patient Protection and Affordable Care Act (ACA) and the national debate preceding its passage typify the different treatment of testing and abortion as maternal health care. The question of how the ACA would treat abortion threatened to derail congressional negotiations over the legislation. More specifically, the ACA will practically reduce health care insurance coverage for abortions at the same time that it provides incentives to test and screen as part of routine maternal health care and preventative services. On the one hand, the ACA excludes abortion as an essential benefit and requires the strict segregation of federal funds for new exchange plans offering abortion coverage. On the other hand, the ACA includes prenatal care as an

6. *See infra* Part I.A. This Article does not explore pre-implantation genetic diagnosis (PGD), although similar ethical issues arise. PGD occurs when physicians test embryos created by artificial reproductive technologies. *See generally* Susannah Baruch, *Preimplantation Genetic Diagnosis and Parental Preferences: Beyond Deadly Disease*, 8 HOUS. J. HEALTH L. & POL'Y 245, 260-61 (2008) (describing debates on whether to discard embryos for non-medical characteristics like sex, for late onset disorders, or for the purpose of having a child *with* a disability like deafness); Joann Bodurtha & Jerome F. Strauss, *Genomics and Perinatal Care*, 366 NEW. ENG. J. MED. 64, 65 (2012) (exploring the implications of whole gene sequencing and noting that pre-implantation diagnosis is highly accurate and relatively unregulated).

7. *See, e.g.*, Henry T. Greely, *Get Ready for the Flood of Fetal Gene Screening*, 469 NATURE 289, 290 (2011); Laird Jackson & Reed E. Pyeritz, *Molecular Technologies Open New Clinical Genetic Vistas*, 65 HUM. GENOMICS 1, 2-3 (2011).

8. *Id.*

essential benefit and will cover a range of prenatal services, including genetic screening and testing.

This Article provides a snapshot of how current law and practice put genetic testing and abortion on a collision course. It considers how the diminishing option of abortion for many pregnant women and increasing options in prenatal genetic testing produce mixed messages for patients and providers alike.[9] It suggests that termination of pregnancies for reason of fetal anomaly will become a focal point of public policy debates in which questions about the scope of future federal and state regulation will undoubtedly arise.[10] The reduced availability of abortion services nationwide and increasing marginalization of abortion as medical care will influence how providers counsel their patients about post-testing options. Obstetricians recommending testing as a source of valuable information about a woman's pregnancy may be the same physicians unwilling to perform or refer women to termination services. In short, without careful consideration of how prenatal genetic testing and abortion intersect, policy debates may be co-opted by anti-abortion rhetoric, rather than focus on the implications for health care delivery.

The first two parts of this Article briefly describe the state of testing today, future innovations, and the obstacles to and restrictions on abortion services in the United States. The last part considers how similar questions have different answers depending on whether one is discussing testing or abortion—is abortion reproductive health care; what is the nature and scope of informed consent; how should the integrity of health professionals be protected; and what is the value of women's autonomy in making decisions about abortion or testing? Drawing briefly on international experience, the Article concludes with a suggestion about how to reconfigure the current conversation

9. *See generally* R. Alta Charo & Karen H. Rothenberg, *"The Good Mother": The Limits of Reproductive Accountability and Genetic Choice*, *in* WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (discussing the social influences and pressures on mothers' choices regarding testing); Karen H. Rothenberg, *The Law's Response to Reproductive Genetic Testing: Questioning Assumptions About Choice, Causation, and Control,* 8 FETAL DIAGNOSIS & THERAPY 160 (1993) (discussing the role of informed consent and choice (or lack thereof) in the future of the law governing reproductive testing).

10. Greely, *supra* note 7, at 290. S*ee generally* Sonia Suter, *The "Repugnance" Lens of* Gonzales v. Carhart *& Other Theories of Reproductive Rights: Evaluating Advanced Reproductive Technologies*, 76 GEO. WASH. L. REV. 1514, 1518 (2008) (discussing how scientific advances have added complexity to the moral and legal issues surrounding reproductive decision making) [hereinafter Suter, *Carhart*].

in order to understand the interplay of abortion and testing decisions in a more nuanced way.

This Article does not intend to suggest that abortion is the only or always the best option after prenatal testing reveals fetal abnormalities or genetic disorders. To the contrary, skeptics of testing argue that women often feel pressure to choose abortion because of professional and popular bias against disability.[11] Indeed, we take seriously the concern that pairing testing and abortion may suggest that disability is an appropriate rationale for termination of a pregnancy, further marginalizing individuals with certain genetic and physical conditions.[12] Our purpose is to highlight that the current stigmatization of abortion as health care leads to an impoverished discourse on why and when to test prenatally. Ultimately, we argue that policy must take account of the increasing gap between law and practice, which could potentially become too wide and the consequences for women and their families become too severe.

I. THE REGULATION OF PRENATAL GENETIC TESTING AND SCREENING

The trend in prenatal genetic screening and testing points toward providing services earlier in pregnancy for broader categories of women. Women will soon have much more information about their pregnancies at lower cost and risk than ever before. In response to advancing technology, professional organizations, scholars, and health professionals have called for better counseling for women before and after screening or testing as well as guidelines about what disorders can be tested for and what results mean.

A. Current Testing and Screening

Most women, after learning they are pregnant, have their first prenatal visit between eight and twelve weeks of gestation.[13] Historically, an obstetrician would rely only on the pregnant woman's family medical history and maternal age to gauge whether she should test

11. Rothenberg, *supra* note 9, at 162; *see* discussion *infra* Part III.B (discussing the disability critique of expanded testing options).

12. *See generally* Mary Crossley & Lois Shepherd, *Genes and Disability: Questions at the Crossroads*, 30 FLA. ST. U. L. REV. xi (2003) (summarizing the discussion of marginalization in a symposium on genes and disability).

13. Ruth M. Farrell et al., *Risk and Uncertainty: Shifting Decision Making for Aneuploidy Screening to the First Trimester of Pregnancy*, 13 GENETICS IN MED. 429, 435 (2011).

cells from the fetus. Modernly, physicians routinely use serum screening (a blood sample from the mother) and ultrasound screening techniques to assess the risk of a fetal genetic disorder.[14] Serum and ultrasound screenings before twenty weeks of gestation are "as commonplace and widely accepted as some of the more routine aspects of prenatal care"[15] for women of all ages and family histories. For example, in 2007, the American Congress of Obstetricians and Gynecologists (ACOG), the leading professional organization for obstetricians and other reproductive health professionals, published a practice bulletin recommending that obstetricians screen all pregnant women before twenty weeks gestation, regardless of maternal age.[16]

Although screening has traditionally focused on the detection of aneuploidies, which are abnormalities in the number of chromosomes,[17] patients can screen for over four hundred genetic disorders[18] and normally screen for common mutations and population-based diseases.[19] There are, however, limitations regarding what screening can tell potential parents. For serum screenings, biochemical markers suggestive of certain disorders change dramatically between the first and second trimesters, making an accurate determination of fetal age necessary.[20] The usefulness of ultrasound screening depends on the clarity of the sonogram image, which becomes sharper as a fetus develops.[21] For these reasons, some health professionals suggest that women screen in both the first and second trimesters if indicated.

Ultrasounds or blood tests only provide a probable risk that a fetus carries a genetic disorder, based on the particular screening method and patient-specific factors.[22] This risk is normally expressed

14. Deborah A. Driscoll & Susan J. Gross, *ACMG Practice Guidelines: Screening for Fetal Aneuploidy & Neural Tube Defects*, 11 GENETICS IN MED. 818, 818-21 (2009).

15. Sonia Suter, *The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 234 (2002) [hereinafter Suter, *Prenatal Testing*].

16. American Cong. of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities*, 109 OBSTETRICS & GYNECOLOGY 217, 217-220 (2007) [hereinafter *ACOG Practice Bulletin*].

17. The most common aneuploidy, Down syndrome, is caused by having three copies of chromosome 21 (a trisomy) and occurs in 1 in 800 live births. Siobhan M. Dolan, *Prenatal Genetic Testing*, 38 PEDIATRIC ANNALS 426, 426 (2009).

18. Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J.L. & GENDER 425, 438 (2006).

19. Bodurtha & Strauss, *supra* note 6, at 65.

20. Peter Wieacker & Johannes Steinhard, *The Prenatal Diagnosis of Genetic Diseases*, 107 DEUTSCHES ÄRZTEBLATT INT'L 857, 859 (2010).

21. *Id.* at 858-59.

22. The "quad screen," named for the four proteins and hormones it measures in the mother's blood, can signal the presence of chromosomal abnormalities. N.J. Wald et al., *Prenatal Screening for Down's Syndrome Using Inhibin-A as a Serum Marker*, 16 PRENATAL DIAGNOSIS

as a percentage that represents the likelihood of a genetic condition.[23] If it appears that there is a moderately-high or high-level of risk, based on family history or screening, physicians will recommend testing via amniocentesis or chorionic villus sampling (CVS).[24] Amniocentesis and CVS, in which fetal cells are collected and tested for a select panel of disorders, have been the primary means for prenatal genetic testing.[25] Each procedure requires extracting cells from the fetus in utero, either through the mother's abdomen or vagina. Both procedures carry around a 1% risk of miscarriage.[26]

Amniocentesis is performed at fifteen to seventeen weeks of gestation with results in about two weeks.[27] CVS can be performed from ten to fourteen weeks of gestation,[28] and results can be obtained in one to two weeks.[29] Because women receive screenings first, they often receive testing results in the second trimester. Due to the small risk of miscarriage and the late timing, discomfort, and costs of the procedures, only two percent of pregnant women currently undergo invasive testing.[30] Moreover, general practice is to test for "no more than a few dozen genes,"[31] and testing, like screening, has its limits. Knowing the genotype of a fetus does not mean physicians or parents can know with certainty how the disorder or characteristic will be ex-

143, 143-53 (1996); *see also* Jackson & Pyeritz, *supra* note 7, at 1. Screening normally consists of both ultrasound and biochemical tests of the mother's blood. Ultrasounds can detect physical anomalies, such as increased nuchal translucency (the amount of fluid found at the back of the fetus' neck), which is associated with trisomies like Down syndrome and neural tube defects. Dolan, *supra* note 17, at 428.

23. *See* Jennifer Czerwinski et al., *Maternal Serum Screening: Results Disclosure, Anxiety, & Risk Perception*, 27 AM. J. PERINATOLOGY 279, 281 (2010). Some screening methods can have high false positives, while other methods are limited by false negatives. Mary E. Norton, *Genetic Screening & Counseling*, 20 CURRENT OPINION IN OBSTETRICS & GYNECOLOGY 157, 160 (2008).

24. Bodurtha & Strauss, *supra* note 6, at 64.

25. A third method, cordocentesis, which targets the fetus's umbilical cord, is rarely employed because it is difficult to administer. Edith Cheng & Vern L. Katz, *Reproductive Genetics: Gene Structure, Mutation, Molecular Tools, Types of Inheritance, Counseling Issues, Oncogenes*, *in* COMPREHENSIVE GYNECOLOGY 34 (Vern L. Katz et al., 5th ed. 2007).

26. Wieacker & Steinhard, *supra* note 20, at 858.

27. *Id.*

28. *Id.*

29. *Id.*

30. Greely, *supra* note 7, at 289 (noting that the percentage of women who test is small because most women are not considered "at risk" and do not carry pregnancies with genetic complications).

31. Greer Donley et al., *Prenatal Whole Genome Sequencing: Just Because We Can, Should We?*, HASTING CTR. REP. (forthcoming) (on file with authors).

pressed.[32] Some genetic conditions may be expressed only partially, ranging from mild to severe symptoms.[33]

Early and on-going counseling before and after testing can help patients interpret screening and testing results.[34] But often women are not given counseling until after screening and before testing. In theory, patients should receive information about "detection and false-positive rates, advantages, disadvantages, and limitations, as well as the risks and benefits of diagnostic procedures."[35] Included in "advantages, disadvantages" should be counseling about options *after* testing, such as terminating the pregnancy, attempting to treat the condition in utero, managing a pregnancy or delivery, or raising a child with the condition at issue. Yet obstetricians generally receive little training on how to counsel a patient before and after genetic testing.[36] Genetic counselors are in demand but are in short supply, and many health care professionals consider themselves to be inadequately prepared to counsel patients about screening generally.[37]

Two innovations promise to change the scope of prenatal genetic testing: the ability to collect fetal DNA through non-invasive techniques and the use of that DNA to sequence the genome of a fetus. As noted, collecting fetal DNA through amniocentesis or CVS is a costly, potentially painful process that occurs later in pregnancy. New techniques will make it possible to isolate fetal cells or cell-free fetal DNA that cross the placental barrier into the maternal bloodstream.[38] The present limitation to the clinical availability of this non-invasive

32. Melissa S. Savage et al., *Evolving Applications of Microarray Analysis in Prenatal Diagnosis*, 23 CURRENT OPINION OBSTETRICS & GYNECOLOGY 103, 104 (2011) (noting that phenotype is unpredictable and "uncertain results can make counseling and parental decisions about pregnancy termination difficult").

33. *Id.* at 106.

34. *Id.* at 107.

35. *ACOG Practice Bulletin*, *supra* note 16, at 219.

36. Peter A. Benn & Audrey R. Chapman, *Ethical Challenges in Providing Noninvasive Prenatal Diagnosis*, 22 CURRENT OPINION IN OBSTETRICS & GYNECOLOGY 128, 131 (2010).

37. Farrell et al., *supra* note 13, at 7.

38. Zhouwei Huang et al., *Novel Approaches to Manipulating Foetal Cells in the Maternal Circulation for Non-Invasive Prenatal Diagnosis of the Unborn Child*, 112 J. CELLULAR BIOCHEMISTRY 1475, 1485 (2011). Fetal DNA only constitutes around "3-10% of total amount of plasma DNA in the maternal circulation." Sinuhe Hahn et al., *Fetal Cells in Maternal Blood: Current & Future Perspectives*, 4 MOLECULAR HUM. REPROD. 515, 516 (1998); W.Y. Tsui et al., *Epigenetic Approaches for the Detection of Fetal DNA in Maternal Plasma*, 1 CHIMERISM 30, 30-35 (2010). A non-invasive test for the identification of Down syndrome has already been introduced. *Sequenom Center for Molecular Medicine Announces Lanuch of Maternit21 Noninvasive Prenatal Test for Down Syndrome*, PRNEWSWIRE (Oct. 17, 2011), http://prenewswire.com/news-releases/sequenom-center-for-molecular-medicine-announces-launch-of-maternit21-noninvasive-prenatal-test-for-down-syndrome-131974043.html.

testing is that there are no reliable markers for sorting fetal cells (or DNA from fetal cells) and DNA of the mother or of prior pregnancies.[39] When a reliable fetal cell marker can be used, only ten milliliters of maternal blood, collected at eight to twelve weeks of gestation,[40] will be needed to analyze fetal DNA.[41] Moreover, new DNA sequencing technologies, and whole genome sequencing, will reveal to parents information beyond diagnoses of severe genetic disorders.[42] Whole genome sequencing, when part of clinical care, will also "produce variants of unknown significance, non-medical genetic markers, carrier statuses, susceptibility genes, and genes expressing conditions with late onset."[43] Many believe non-invasive testing, paired with advances in sequencing, will soon become the standard: it will become cost-effective[44] and ultimately accessible to practicing obstetricians, potentially for use in lieu of current screening.[45]

Perhaps as important as these scientific developments, the legal infrastructure exists to support the introduction of non-invasive testing and whole gene sequencing in clinical settings. As the next two sections explain, the regulation of testing can accommodate changes in technology; the tort system penalizes physicians as negligent who do not offer testing; and health care reform portends incentives to pay for screening and testing.

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39. Michele G. Curtis et al., *Flow Cytometric Methods for Prenatal & Neonatal Diagnosis*, 363 J. IMMUNIZATION METHODS 198, 198-209 (2011); Ying Li et al., *Detection of Paternally Inherited Fetal Point Mutations for B- Thalassemia Using Size-Fractionated Cell-Free DNA in Maternal Plasma*, 293 J. AM. MED. ASS'N. 843, 844 (2005).

40. Cell-free fetal DNA can be detected in maternal serum at as early as five weeks of gestation. Y.M. Lo et al., *Presence of Fetal DNA in Maternal Plasma & Serum*, 350 LANCET 485, 485-87 (1997).

41. *See* Carolyn Jacobs Chachkin, *What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care*, 33 AM. J.L. & MED. 9, 20 (2007).

42. Donley et al., *supra* note 31, at 1; W. Gregory Feero et al., *Genomic Medicine—An Updated Primer,* 362 NEW ENG. J. MED. 2001, 2001 (2010) (describing the basic innovations in genomic medicine); Geoffrey Carr, *Biology 2.0, A Special Report on Human Genome*, ECONOMIST, June 17, 2010, http://www.economist.com/node/16349358 (describing the speed of development of and reduced cost of sequencing technology).

43. Donley et al., *supra* note 31, at 2; *see infra* Part III (discussing the relationship of whole genome sequencing to informed consent and decision-making in prenatal genetic testing).

44. As Professor Jaime King explains, the cost of invasive testing is likely to decrease. Technology will evolve to allow testing of multiple regions of DNA, and DNA sequencing is becoming cheaper. Jaime King, *And Genetic Testing for All . . . The Coming Revolution in Non-Invasive Prenatal Genetic Testing*, 42 RUTGERS L.J. (forthcoming 2011).

45. King argues that if testing is used to confirm screening, then some women are likely to have testing if it means faster results at no physical risk. *Id.* at n.96.

B. Federal Regulation and the ACA

Early legislation wrestled with tensions around the voluntariness of testing, the content of information and counseling patients received, and the instances in which amniocentesis should be performed. Congress passed the now-repealed National Genetic Diseases Act in 1976, which provided detailed regulations and separate grants to the states to establish programs for genetic services.[46] By the 1980s, this funding was folded into the Maternal and Child Health Services Block Grant, forcing genetic services programs to compete for funding with programs for maternal and child health and for children with special needs, among others.[47] In the 1990s, the Secretary of Health and Human Services (HHS) retained authority to develop genetic research and other programs, but with no clear source of funds for the Secretary to draw upon.[48]

Contemporary federal legislation addresses non-discrimination based on genetic information and support services for families caring for children with genetic conditions. For example, in 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA) and the Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCA). At the risk of oversimplification,[49] GINA forbids certain employers and group health plans or health insurance issuers from discriminating against individuals based on their genetic information.[50] The PPDCA enables the Secretary of HHS to issue grants to organizations that collect information on genetic disorders and assist

46. Ellen Wright Clayton, *What the Law Says About Reproductive Genetic Testing and What It Doesn't, in* WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 131, 134 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

47. *Id.* at 134-35.

48. *Id.* at 135.

49. For further explanation of the provisions of GINA and debates surrounding its enactment and enforcement, see Kathy L. Hudson et al., *Keeping Pace with the Times—The Genetic Information Nondiscrimination Act of 2008*, 358 NEW. ENG. J. MED. 2661 (2008) (describing the provisions of GINA); Amy L. McGuire & Mary Anderlik Majumder, *Two Cheers for GINA?*, 1 GENOME MED. 6.1, 6.1 (2009) (summarizing the debates around GINA); Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 601 (2011) (analyzing GINA's approach to discrimination).

50. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 202(a)(2), 122 Stat. 881, 882 (2008). Title I of GINA forbids insurers from using genetic information as the basis for a denial of coverage as a preexisting condition. *Id.* § 102(b)(1)(B). Title II of GINA prohibits employers with fifteen or more employees from requesting, requiring, purchasing or disclosing employee genetic information. Recently, the Equal Employment Opportunity Commission issued final regulations interpreting GINA's requirements of employers. *See generally* Thomas H. Christopher et al., *EEOC Issues Final Regulations on Genetic Discrimination in the Workplace*, 36 EMPLOYEE RELATIONS L.J. 45 (2011) (describing the regulations and guidance by the EEOC).

families raising children with Down syndrome or other prenatally or postnatally diagnosed conditions.[51] 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 disorders.[52] Indeed, the PPDCA reflects a bi-partisan effort that brought together pro-life, pro-choice, and disability advocates around the important goal of supporting parents caring for children with genetic conditions.[53]

In 2001, the Department of HHS Advisory Committee on Genetic Testing recommended FDA oversight over certain genetic tests (prenatal or otherwise) in a report titled, *Enhancing the Oversight of Genetic Tests*.[54] Federal intervention is decidedly on the side of fostering access to genetic information and reducing what Congress has perceived as harmful consequences of that information, such as discrimination.

There is also federal willingness to fund some testing and screening services. Medicaid programs cover the costs of prenatal genetic screenings in thirty-six states and the District of Columbia[55] and testing in forty-seven states for particular categories of women. In addition, Medicaid programs in twenty-four states cover the costs of genetic counseling.[56] Although state Medicaid programs vary, Congress has made clear that testing and abortion are not synonymous.

51. Support services include education programs for health care providers, a hotline for parents, and an information distribution center. The PPDCA also establishes a national registry of families willing to adopt children with genetic conditions. Prenatally & Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, § 3, 122 Stat. 4051, 4051-54 (2008) (amending the Public Health Service Act 42, U.S.C. § 254c-8(e) (2006)).

52. *See* John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469, 477 (2011).

53. *Id.* Muller critiques the PPDCA for emphasizing distribution of accurate information but not for giving guidance to parents about how to act upon that information. *Id.* at 478.

54. Secretary's Advisory Committee on Genetic Testing, 65 Fed. Reg. 76,643, 76,643 (Dec. 7, 2000). The report called for test-specific fact sheets that would include the definition and purpose of each test; the condition tested and the test's clinical utility; and the cost of the test and billing/reimbursement information. Secretary's Advisory Committee on Genetic Testing, 65 Fed. Reg. 77,631, 77,632 (Dec. 12, 2000).

55. USHA RANJI ET AL., HENRY J. KAISER FAM. FOUND., STATE MEDICAID COVERAGE OF PERINATAL SERVICES: SUMMARY OF STATE FINDINGS 14 (2009), *available at* http://www.kff.org/womenshealth/upload/8014.pdf.

56. COMM. ON PREVENTIVE SERVS. FOR WOMEN, INST. OF MED., CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS 61 (2011) [hereinafter CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS], *available at* http://www.nap.edu/catalog.php?record_id=13181.

No Medicaid programs may cover abortion costs unless the mother's life is in danger or the pregnancy arises from rape or incest.[57]

The ACA will expand testing and screening services by increasing Medicaid coverage. The ACA promises to provide new health insurance coverage to approximately thirteen million women of childbearing age through extending Medicaid eligibility[58] or through state-based exchanges.[59] The expansion of Medicaid will be of significant value to pregnant women: over forty percent of U.S. women rely on Medicaid for prenatal care.[60] By introducing higher incomes caps for Medicaid eligibility, even more women will qualify for low-cost or free testing and screening.[61]

The ACA also outlines requirements of what "essential benefits" health insurance plans must offer without cost-sharing (co-payments, co-insurance, or deductibles, for example). Maternity and newborn care is an essential health care benefit, although the ACA does not explicitly reference prenatal genetic testing or screening.[62] In December, the Obama Administration decided that each state, rather than the Secretary of HHS, would determine the definition and scope of essential benefits, leaving the inclusion of testing and screening as prenatal care for states to determine.[63]

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57. *Id. See infra* Part II.A (describing the Hyde Amendment).

58. USHA RANJI ET AL., HENRY J. KAISER FAM. FOUND., FOCUS ON HEALTH REFORM 1, 6 n.1 (2010), *available at* http://www.kff.org/healthreform/upload/8021.pdf:

> The ACA will expand health care coverage to many of the nation's uninsured by extending Medicaid eligibility to all qualifying individuals with incomes up to 138% of the federal poverty level (FPL).
>
> . . . .
>
> Legislation extends Medicaid coverage to all individuals with incomes up to 133% of the poverty level (FPL) and includes a provision to disregard first 5% of income, effectively extending Medicaid to all individuals with incomes up to 138% FPL.

Id.

59. *Id.* at 1 ("Uninsured individuals with incomes above 138% FPL will be able to purchase coverage in new state-based insurance exchanges that will act as marketplaces, open to all qualifying, uninsured individuals and small businesses with up to 100 employees.").

60. *Id.* Although federal law requires coverage of pregnant women with family incomes up to 133% of the FPL, states may permit higher-income thresholds. *Id.* States like Texas and South Carolina, with over fifty percent of the state's pregnant women relying on Medicaid, permit women with 185% of the FPL to qualify for Medicaid. *Id.* at 5, 11.

61. Alina Salganicoff & Jane An, *Making the Most of Medicaid: Promoting the Health of Women and Infants with Preconception Care*, 18 WOMEN'S HEALTH ISSUES S41, S41-46 (2008); Chachkin, *supra* note 41, at 44 (citing a survey of forty-six state Medicaid programs that cover amniocentesis or CVS).

62. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1302(b)(1)(D), 124 Stat. 119, 163 (2010).

63. *Id.* § 1302(b)(2)(3); Robert Pear, *Health Care Law Will Let States Tailor Benefits,* N.Y. TIMES, Dec. 16, 2011, at 1.

Prenatal genetic testing and screening might also be part of the preventive services that qualified health plans must cover.[64] The definitions and scope of preventative services were set out in guidelines issued by the Health Resources and Services Administration (HRSA). In August 2011, the Secretary of HHS approved the guidelines submitted by the HRSA. Among other important features,[65] the regulations include a well-woman visit, which incorporates prenatal care, in the definition of preventative treatment.[66] Although neither the guidelines nor the recommendations spell out what prenatal care involves, an Institute of Medicine (IOM) report, on which the HRSA relied, suggests that screening and testing are part of prenatal care.[67] In describing the routine coverage of private plans and public programs, the IOM report stated: "Pregnant women should receive . . . prenatal screening and testing for neural tube defects (for all women at elevated risk) and chromosomal abnormalities (for all women age 35 years and older), including, but not limited to amniocentesis, chorionic villus sampling, and ultrasound."[68]

These recommendations represent the present consensus among health care professionals about which women should have testing or screening (women of advanced maternal age) and for what conditions (disorders that traditional technologies can recognize). Because the IOM Committee on Preventative Services for Women is tasked with "regularly updating the preventative screenings and services to be considered," recommendations on genetic testing and screening can

64. *See* Patient Protection and Affordable Care Act §1001. Employers will also be able to adjust the premiums of health plans they offer employees based on employee involvement in wellness and preventative care programs. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 15.

65. Preventative services also include contraceptive methods and counseling; screening for gestational diabetes; human papillomavirus testing; counseling for sexually transmitted infections; counseling and screening for human immune-deficiency virus; breastfeeding support, supplies and counseling; and screening and counseling for interpersonal and domestic violence. U.S. Dep't of Health & Human Servs., *Women's Preventive Services: Required Health Plan Coverage Guidelines, Affordable Care Act Expands Prevention Coverage for Women's Health and Well-Being*, HRSA, http://www.hrsa.gov/womensguidelines (last visited Mar. 8, 2012).

66. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 12.

67. U.S. Dep't of Health & Human Servs., *supra* note 65. The IOM formed a committee to analyze preventative services for women and to consult organizations and individuals. The comments refer to genetic screening of parent, as a preventative measure, but not to genetic testing or screening of fetuses.

68. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 56-57.

change over time and may create a forum in which new technology will influence revisions of HHS policy.[69]

C. Examples of State Regulation

Like the federal government, states generally do not regulate the specifics of prenatal genetic testing and screening and do not typically regulate how health care professionals offer screening or explain or treat genetic disorders.[70] However, the rules governing health care insurance practices, the tort system, and the regulation of genetic counselors reflect current trends in clinical care.

First, some states regulate what screening and testing services must be included in benefit plans.[71] For example, California, Massachusetts, Ohio,[72] and Washington[73] explicitly require health insurance plans to cover prenatal genetic testing and screening, while Louisiana and Illinois require limited insurance coverage for screenings of particular disorders. California requires that all plans covering prenatal care must include a maternal blood screen and genetic testing for particular disorders.[74] The Massachusetts health insurance program, which provides state insurance for those earning below 200% of the federal poverty line, covers amniocentesis and all pregnancy costs.[75] Louisiana only requires insurance plans to cover screening for cleft lift/palate,[76] and Illinois requires insurance plans to cover prenatal

69. *Id.* at 1.

70. California and Iowa are exceptions in this regard: both states require obstetricians to give women an opportunity to screen for genetic and other anomalies. CAL. HEALTH & SAFETY CODE § 124980 (Deering 2012); IOWA CODE § 136A.1 (2011).

71. Whether services are covered by an insurance plan usually depends on whether the service is "medically necessary" or indicative of the standard of care. Chachkin, *supra* note 41, at 39. The norm is for insurance companies, not the state, to define "medically necessary." State laws, if they speak to the issue, define "medically necessary" broadly. For example, the Illinois Department of Insurance defines medically necessary services as "health care services and supplies provided by a health care provider appropriate to the evaluation and treatment of disease, condition, illness or injury and consistent with the applicable standard of care, including the evaluation of experimental and/or investigational services, procedures, drugs or devices." ILL. DEP'T OF INS., ILLINOIS INSURANCE FACTS: MEDICAL NECESSITY 1 (2010), *available at* http://insurance.illinois.gov/healthinsurance/MedicalNecessity.pdf.

72. OHIO REV. CODE ANN. § 1751.01 (LexisNexis 2012); OHIO ADMIN. CODE § 5101:3-4-07 (2012). *But see* OHIO REV. CODE ANN. § 4112.01(B) (LexisNexis 2011) (stating that an employer is not required to pay for health insurance benefits for an abortion where the mother's life is not in danger).

73. WASH. REV. CODE ANN. § 48.21.244 (LexisNexis 2012); WASH. REV. CODE ANN. § 48.44.344 (LexisNexis 2012); WASH. REV. CODE ANN. § 48.46.375 (2012).

74. CAL. INS. CODE §§ 10123.184, .9 (Deering 2012).

75. 130 MASS. CODE REGS § 522.005 (2012).

76. LA. REV. STAT. ANN. § 22:1026 (2012).

HIV screenings.[77] Alabama, Arkansas, Minnesota, New Hampshire, and Wisconsin appear to require coverage of prenatal genetic testing and screening because they require insurers to cover prenatal care that is medically necessary.[78] Generally, insurers cover amniocentesis or CVS for women over age thirty-five or with indicative family histories and positive screens, although companies differ in how they define "medically necessary" genetic testing and screening.[79]

Second, the growth of genetic testing and screening has influenced changes to the licensure of genetic counselors across the country. Thirteen states have statutes dealing with licensing genetic counselors, and six more states are debating licensing laws.[80] The language of state statutes is based, sometimes verbatim, on recommendations by the National Society of Genetic Counselors (NSCG).[81] For example, Delaware's law establishes a Genetic Counselor Advisory Council to issue regulations and to review license applications.[82] In 2006, the National Conference of State Legislatures encouraged states to enumerate the services licensed genetic counselors must provide and distributed a policy brief for states to follow.[83]

Finally, in most states patients may sue physicians in tort for failing to test or screen if a child is born with a physical or genetic disabil-

77. 215 ILL. COMP. STAT. ANN. 5/356z.1 (LexisNexis 2012).

78. *See, e.g.*, N.H. REV. STAT. ANN. § 417-D:2-a (Lexis Nexis 2012) ("Insurers shall not deny payment for services that are within standards of . . . generally accepted medical practice as reflected by scientific and peer medical literature and recognized within the organized medical community in the state of New Hampshire."). *But see* WIS. ADMIN. CODE COMM'R OF INS. § 8.72(14)(a) (2012) (mandating companies cover "[p]renatal services normally associated with pregnancy").

79. Aetna, for example, will cover maternal serum screening in the first trimester, but considers serum screening in the second trimester to be experimental. *Clinical Policy Bulletin: Serum Marker Screening for Down Syndrome*, AETNA (Mar. 8, 2012, 8:55 PM), http://www.aetna.com/cpb/medical/data/400_499/0464.html.

80. Jessica L. Mester et al., *Perceptions of Licensure: A Survey of Michigan Genetic Counselors*, 18 J. GENETIC COUNS. 357, 358-365 (2009) (citing laws of California, Delaware, Hawaii, Illinois, Indiana, Massachusetts, New Jersey, New Mexico, Oklahoma, South Dakota, Tennessee, Utah, and Washington).

81. *State Licensure for Genetic Counselors*, NAT'L SOC'Y OF GENETIC COUNSELORS, http://www.nsgc.org/Advocacy/StateLicensureforGeneticCounselors/tabid/320/Default.aspx (last visited Jan. 8, 2012).

82. DEL. CODE ANN. tit. 24, § 1799I (2011). The statute also makes plain that applicants must have ABGC or ABMG certification and sets out grounds for disciplinary action, which include "illegal, competent or negligent conduct" or violation of the NSGC's code of ethics. *Id.* §§ 1799J, 1799P.

83. The Conference called on states to detail requirements for physician supervision of counselors, set out minimum qualifications for counselors, described penalties for unprofessional conduct, and addressed other issues, such as patients' confidentiality and continuing education for counselors. Alissa Johnson, *NCSL Genetics Brief: Genetic Counselor Licensing*, NAT'L CONF. OF STATE LEGISLATURES (July 2006), http://www.ncsl.org/default.aspx?tabid=14276.

ity. More than half of states permit wrongful birth actions:[84] suits for damages brought by the parents who claim that their child's birth would have been prevented but for the negligence of the defendant physician, who failed to disclose testing options or failed to provide the correct test results.[85] By contrast, most state courts will not permit children to bring wrongful life claims.[86] Wrongful life claims are actions brought by the child for damages associated with his or her birth on the theory that but for the defendant physician's negligence, he or she would have never have been born.[87]

The paucity of regulation at state and federal levels creates space for the introduction of new forms of testing and DNA sequencing as part of routine prenatal care. As the next Part highlights, there is the opposite regulatory response to abortion, where laws closely scrutinize the information given to patients and pregnant women's choices.

II. THE DECLINING AVAILABILITY OF ABORTION SERVICES

As prenatal genetic testing and screening expand, abortion services have become less available, and abortion politics in the United States have never been more contentious. In the last several years, federal and state legislation has restricted abortion care on a number of fronts–reducing funding for services; banning the types or limiting the timing of procedures; imposing liability on providers through the regulation of facilities, licenses, and physician conduct; and requiring patients to submit to counseling, or other "informed consent" requirements, such as ultrasound viewing.[88] These laws have created a remarkably different picture of abortion accessibility over the last several decades, and legislation currently before statehouses foretell of additional restrictions.

84. *See* Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 160 (2005).

85. *See* Charo & Rothenberg, *supra* note 9, at 112; *see also* Wilson v. Kuenzi, 751 S.W.2d 741, 743 (Mo. 1988).

86. *See* Jillian T. Stein, *Backdoor Eugenics: The Troubling Implications of Certain Damages Awards in Wrongful Birth and Wrongful Life Claims*, 40 SETON HALL L. REV. 1117, 1132, 1135 (2010); *see, e.g.*, Curlender v. Bio-Science Labs., 165 Cal. Rptr. 477, 481, 489-90 (Cal. Ct. App. 1980); Procanik v. Cillo, 478 A.2d 755, 762, 764 (N.J. 1984); Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 496 (Wash. 1983); s*ee also* Kassama v. Magat, 368 Md. 113, 137, 138 (Md. 2002) (listing California, New Jersey, and Washington as states that recognize wrongful life claims).

87. *See Kuenzi*, 751 S.W.2d at 743.

88. *See* Erik Eckholm, *Several States Forbid Abortion After 20 Weeks*, N.Y. TIMES, June 27, 2011, at A10; s*ee also* Emily Bazelon, *The Reincarnation of Pro-Life*, N.Y. TIMES, May 29, 2011, at MM13.

Our purpose is to note the legal trends that have had real consequences for women's pregnancy choices. Terminating a pregnancy after discovering fetal anomaly has not only been a longstanding option, but also, in some cases, an important health care intervention.[89] However, the disassociation of abortion as health care has and will shape the choices pregnant women make after prenatal genetic testing.[90]

A. Funding

Who pays for abortion has been at the center of public debate for over thirty years and, as noted, was a sticking point in negotiations of the ACA. Known as the "Hyde Amendment," Congress has passed legislation every year since 1976 to exclude abortion from Medicaid coverage except when the woman's life is at risk or where pregnancy is the result of rape or incest.[91] Some states fund abortions (with state money) on broader grounds. But most states follow Hyde or ban state-based funding for any abortion services or referrals.[92] Fifteen states have taken the additional step of prohibiting insurance plans that cover public employees from offering abortion benefits.[93] Of states limiting public support for abortion, Mississippi and Virginia explicitly permit Medicaid funding for fetal abnormality.[94]

In 2009, a fresh battle over insurance coverage of abortion erupted in negotiations over new benefits plans operating under pro-

89. For example, testing can reveal information about fetal anomaly or other characteristics of the fetus that could threaten the mother's health. King, *supra* note 44, at 6.

90. B. Jessie Hill, *Reproductive Rights as Health Care Rights*, 18 COLUM. J. GENDER & L. 501, 502 (2009).

91. RANJI ET AL., *supra* note 58, at 2. Federal limits on abortion funding have been extended to plans for federal employees, participants in the Indian Health Service, and women in the military. *Id.*

92. NAT'L NETWORK OF ABORTION FUNDS, ABORTION FUNDING: A MATTER OF JUSTICE (2005), *available at* http://www.fundabortionnow.org/sites/default/files/exec_summary_abortion_funding_a_matter_of_justice.pdf (noting thirty-three states in 2005 did not permit use of state Medicaid or other public funds for low-income women's abortion services). Only four of the seventeen states that use public funds for abortion services do so voluntarily; the rest provide state funds because of a court order. *See also* Am. Civ. Liberties Union, *Public Funding for Abortion*, AM. CIV. LIBERTIES UNION, http://www.aclu.org/files/FilesPDFs/map.pdf (last visited Mar. 8, 2012) (map showing which states fund abortion for low-income women through a legislative act or because of a court order).

93. GUTTMACHER INST., STATE POLICIES IN BRIEF: RESTRICTING INSURANCE COVERAGE OF ABORTION (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_RICA.pdf (last updated Apr. 1, 2012). Two of these states, Louisiana and Tennessee, permit no abortion coverage, while the rest permit coverage for life endangerment only; for threat to life or health; and in instances of rape or incest. *Id.*

94. *See* GUTTMACHER INST., STATE POLICIES IN BRIEF: STATE FUNDING FOR ABORTION UNDER MEDICAID (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_SFAM.pdf (last updated Apr. 1, 2012).

posed state insurance exchanges.[95] The purpose of the exchanges is to help individuals and small businesses (those unlikely to avail of employer insurance plans or purchase benefits for employees) buy private health care coverage by creating a federally-subsidized, state-based market. Whether abortion would be offered by plans in new health care exchanges was controversial for all bills introduced in the House and the Senate, as well as the reconciliation bill approved by Congress and signed by President Obama.[96] The ACA reflects a tense compromise reached by the legislation's drafters, embodied in legislative language known as the Nelson Amendment.

The Nelson Amendment excludes abortion as an essential benefit offered by plans participating in state exchanges, except when a woman's life is threatened and in instances of rape or incest (the Hyde grounds).[97] Moreover, plans participating in state exchanges may offer abortion coverage but must comply with rules that ensure no federal money subsidizes that care.[98] First, insurers must offer at least one plan that does not cover abortion. Second, for plans that cover abortion, the insurance company must collect two premiums from plan members—one for abortion benefits and one for everything else.[99] The cost of the abortion benefit must be at least one dollar per enrollee per month.[100] Finally, the ACA prohibits plans from discriminating against any physician participant that is unwilling to provide abortion care.[101] Fifteen states have already passed laws prohibiting insurance companies participating in state exchanges from offering

95. *See* Susan A. Cohen, *Insurance Coverage of Abortion: The Battle to Date & the Battle to Come*, 13 POL'Y REV. 1, 2 (2010), *available at* http://www.guttmacher.org/pubs/gpr/13/4/gpr130402.pdf (summarizing the debate in Congress over the ACA's treatment of abortion).

96. The Senate Finance bill, for example, prohibited abortion coverage from being required as part of a minimum benefits package and required segregation of public funds in private payments for plans that cover abortion services on non-Hyde grounds. For a summary, see *Health Care Reform Proposals*, KAISER FAMILY FOUND., http://www.kff.org/healthreform/upload/healthreform_tri_full.pdf (last modified Oct. 15, 2009).

97. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1303(a)(1)(A)(i), 124 Stat. 119 (2010).

98. *Id.* § 1303(a)(1)(B)(i).

99. *Id.* § 1303(a)(2)(B). The cost of the abortion benefit must be at least one dollar per enrollee per month. *Id.* § 1303(a)(2)(C)(ii)(II).

100. *Id.* Traditionally, abortion as a health care service offered by health insurance plans was considered a cost saving measure and thus had a negative actuarial value. *See generally* Roy G. Spece, Jr., *The Purpose Prong of* Casey*'s Undue Burden Test and its Impact on the Constitutionality of Abortion Insurance Restrictions in the Affordable Care Act or Its Progeny*, 33 WHITTIER L. REV. 77, 87-88 (noting earlier legislative attempts to inflate the actuarial figures associated with abortion and to ignore evidence of costs-savings with abortion coverage).

101. *See* Patient Protection and Affordable Care Act §§ 10104(c), 1303(b)(4). State insurance commissions will oversee the separate accounts into which insurance companies must deposit payments for abortion benefits. *Id.* §§ 10104(c), 1303(b)(2)(E)(i).

any coverage for abortion services; another fifteen debated such laws in 2011.[102]

The combination of disincentives (administrative and financial) for insurance companies to offer abortion coverage[103] and the expansion of Medicaid with Hyde restrictions means that the number of women paying out-of-pocket will likely increase.[104] The ACA will create additional administrative costs for health insurance companies offering abortion care in state exchange plans, which companies are likely to pass to consumers in the form of higher premiums. Because consumers may not choose a more expensive plan,[105] some policy analysts suggest that insurers will cut abortion benefits in most plans to save costs,[106] thus further marginalizing abortion.[107]

B. Conditioning Patient Choice

Unlike most medical procedures, states often require patients to observe waiting periods, for providers to deliver scripted counseling and information, and for women to view ultrasound images before an abortion.[108] Thirty-four states require counseling before a termination, with twenty-six of these states detailing what information women must receive. Twenty-six states require a waiting period between counseling and the abortion procedure. Most waiting periods are

102. Karmah Elmusa, *Map of the Day: States Banning Abortion Coverage*, MOTHER JONES, (June 29, 2011), http://motherjones.com/mojo/2011/06/map-state-abortion-coverage-ban. On the federal level, the House of Representatives passed the "No Taxpayer Funding for Abortion Act," which did not receive a Senate vote. H.R. 3, 112th Cong. (2011). The bill prevents employers from taking a tax deduction for insurance plans that include abortion coverage. It also prevents individuals from paying for plans that cover abortion with pretax dollars and flexible health spending accounts or claiming the federal medical care deduction. *Id.* §§ 101, 201, 202.

103. *See* Cohen, *supra* note 95, at 4.

104. In 2002, eighty-seven percent of private plans covered medically necessary abortions. The survey did not capture how many of the plans covered elective abortion that was not medically indicated. Adam Sonfield et al., *U.S. Insurance Coverage of Contraceptives and the Impact of Contraceptive Coverage Mandates, 2002*, 36 PERSP. SEXUAL & REPROD. HEALTH 72, 75-76 (2004), *available at* http://www.guttmacher.org/pubs/psrh/full/3607204.pdf.

105. An IOM report shows that even moderate co-pays for some preventative services "deter patients from receiving those services." CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 19.

106. Cohen, *supra* note 95, at 2-4 (discussing ACA segregation rules and disincentives for abortion coverage).

107. For example, abortion was explicitly left out of the IOM's considerations of what women's preventative care should include. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 21. Arguably, insurance companies may have an incentive to cover abortion if testing reveals fetal abnormality that is very costly to treat.

108. Professor Maya Manian has shown how different informed consent for abortion is from other medical procedures. Maya Manian, *The Irrational Woman: Informed Consent and Abortion Decision-Making*, 224 DUKE J. GENDER L. & POL'Y 223, 244-45 (2009).

twenty-four hours, but some states either impose longer time periods, or require in-person counseling, necessitating two trips to a provider.[109] South Dakota is the outlier, having imposed a seventy-two hour waiting period that is now the subject of litigation.[110]

In the abortion context, the trend is also toward more information, but in the form of guidance that might dissuade a woman from abortion by providing her with details about the fetus or the risks of abortion. States commonly mandate information about the physical or psychological consequences of abortion and about the gestational age of the fetus or fetal development.[111] Eight states require a health professional to describe only negative consequences or risks of abortion. Seven states inaccurately link abortion to the occurrence of breast cancer, and eleven include information about the possibility of fetal pain.[112] Described in more detail in Part III, one variant of so-called informed consent laws garnering recent media attention and judicial review are statutes mandating that providers show patients ultrasound images.

C. Regulations of Facilities and Providers

State laws regulating abortion take on a variety of forms: special licensing requirements, such as admitting privileges at hospitals; regulations of clinic or facility space and design; ambulatory surgical center requirements; special ethics trainings for providers; and detailed record-keeping requirements.[113]

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109. GUTTMACHER INST., STATE POLICIES IN BRIEF: COUNSELING & WAITING PERIODS FOR ABORTION (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_MWPA.pdf (last updated Apr. 1, 2012) (noting that nine states effectively require two trips to an abortion provider); *see also* Ian Vandewalker, *Abortion & Informed Consent: How Biased Counseling Laws Mandate Violations of Medical Ethics*, 19 MICH. J. GENDER & L. (forthcoming 2012) (citing Planned Parenthood of Middle Tenn. v. Sunquist, 38 S.W.3d 1 (Tenn. 2000), which struck down a two-day waiting period).

110. Robin Marty, *South Dakota Mandatory 72 Hour Waiting Period On Hold Until Court Rules on Constitutionality*, RH REALITY CHECK (July 26, 2011, 4:00 PM), http://www.rhrealitycheck.org/blog/2011/07/26/south-dakota-mandatory-hour-waiting-period-hold-until-court-rules-constitutionality.

111. *See* Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 882-83 (1992).

112. GUTTMACHER INST., STATE POLICIES IN BRIEF: ABORTION REPORTING REQUIREMENTS (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_ARR.pdf (last updated Apr. 1, 2012) (noting that eleven state laws refer to fetal pain; thirty-three state laws to gestational age; twenty-five state laws to fetal development; eight state laws only negative psychological responses; seven states inaccurately link breast cancer and abortion).

113. Forty-six states require hospitals, facilities, and physicians to submit regular, confidential reports of abortion procedures to the state government; and, twelve states further require certification that counseling and parental involvement standards were met. *Id.* Interestingly,

A law recently passed in Kansas, and now enjoined by a federal district court, is illustrative.[114] In April 2011, the Kansas legislature passed an act that created a new licensing category for abortion providers. Regulations issued pursuant to the act require expanded waiting room and janitorial supply spaces, as well as physician admitting privileges to hospitals. The regulations gave providers one month to comply with the new law, which was impossible given the time necessary to establish admitting privileges and redesign clinical space.[115]

Perhaps the most significant developments in abortion regulation, with acute relevance to screening and testing, are state attempts to ban specific abortion procedures and abortion after twenty weeks of gestation. *Gonzales v. Carhart*[116] confirmed that the federal government could ban procedures like intact D&E in order to protect the integrity of the medical profession[117] and the emotional health of women (both state interests are examined in the next Part).[118] Moreover, the Court held that medical evidence did not conclusively establish that the procedure was necessary to protect a woman's physical health.[119]

Carhart signaled to state legislatures the willingness of the Supreme Court to permit restrictions in the name of protecting fetal *and* women's health. Another recent restriction on the availability of abortion services are new state laws that prohibit providers from terminating a pregnancy after twenty weeks, which is, in most cases, three or four weeks before viability and in apparent contradiction with *Planned Parenthood of Southeast Pennsylvania v. Casey*.[120]

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fifteen of those forty-six states require reports to list whether the abortion was for reason of fetal abnormality. *Id.*

114. *See* KAN. ADMIN. REGS. § 28-34-133(b) (2012); *see also* Brad Cooper, *Federal Judge Blocks New Abortion Licensing Rules*, KAN. CITY STAR, July 1, 2011, http://www.cafemom.com/group/33200/forums/read/14412489/Fedreal_Judge_blocks_new_abortion_rules_in_Kansas (last visited Mar. 9, 2012).

115. Similar laws have been passed in Virginia and Utah. *See* Kate Sheppard, *Kansas to Shut Down All but One Abortion Clinic Friday*, MOTHER JONES, June 30, 2011, http://motherjones.com/mojo/2011/06.

116. Gonzales v. Carhart, 550 U.S. 124, 124 (2007).

117. *See id.* at 157-58, 160; *see also* Priscilla Smith, *Responsibility for Life: How Abortion Serves Women's Interests in Motherhood*, 17 J.L. & POL'Y 97, 141 (2008).

118. *See Carhart*, 550 U.S. at 159-60.

119. *Id.* at 158, 163-64 ("[T]he State may use its regulatory power to bar certain procedures and substitute others . . . .").

120. The Supreme Court gauged viability at about the twenty-third or twenty-fourth week after the last menstrual cycle. *See* Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 860 (1992). These laws are related to the partial birth abortion litigation, because, as Justice Ginsburg noted in dissent, "partial birth abortion laws" do not account for the point of gestation and thus "blur[ ] the line, firmly drawn in *Casey*, between pre-viability and post-viability abortions."

Thirty-nine states already limit abortion after viability,[121] and the premise of legislation prohibiting abortion at and after twenty weeks is that fetuses can feel pain at that point.[122] As of June 2011, six states passed twenty week bans with exceptions for the pregnant woman's life or in cases of "serious physical impairment of [the woman's] bodily function."[123]

D. Refusals or Conscience Clauses

Federal law and the laws of forty-six states permit individual health care providers and institutions to refuse to perform or to offer abortion services. The first federal conscience clause law, the "Church Amendment," was enacted in 1973 as a direct response to *Roe v. Wade*.[124] The Amendment essentially states that individuals or entities receiving public funds may refuse to perform abortions or sterilization procedures based on moral or religious beliefs.[125] Within five years of the Amendment, almost every state had conscience clause legislation.[126] Additional amendments to the Public Health Services Act and Appropriations Act (the Coats[127] and Weldon[128] Amendments) broadly prohibit the government and recipients of government

Carhart, 550 U.S. at 171 (Ginsburg, J., dissenting). Professors I. Glenn Cohen & Sadath Sayeed also note that the twenty week bans do not require physicians to resuscitate the premature newborn that is born at or before twenty-three weeks. I. Glenn Cohen & Sadath Sayeed, *Fetal Pain, Abortion, Viability, & the Constitution*, 39 J.L. MED. & ETHICS 235, 237 (2011). The common practice is not to resuscitate given the "poor chance of survival without significant disability." *Id.*

121. GUTTMACHER INST., STATE POLICIES IN BRIEF: STATE POLICIES ON LATER ABORTION (2012), http://www.guttmacher.org/statecenter/spibs/spib_PLTA.pdf (last updated Apr. 1, 2012). Twenty of the thirty-nine states limit abortion after viability; five in the third trimester; and fourteen at a certain number of weeks. *Id.*

122. *See, e.g.*, 2010 Neb. B. 1103, 101st Leg. 2d. Sess. (2010), *available at* http://www.nebraskalegislature.gov/FloorDocs/101/PDF/Slip/LB1103.pdf; *see also* Cohen & Sayeed, *supra* note 120, at 238 (refuting that fetuses can "experience" pain at twenty weeks).

123. Florida and Iowa considered similar bills in 2011. Eckholm, *supra* note 88. For example, the exception for women's health in the Nebraska bill is framed as a "condition that so complicates [the woman's] medical condition as to necessitate the abortion of her pregnancy to avert her death or to avert serious risk of substantial and irreversible physical impairment of a major bodily function." Neb. B. 1103, *available at* http://www.nebraskalegislature.gov/FloorDocs/101/PDF/Slip/LB1103.pdf.

124. Health Programs Extension Act, Pub. L. No. 93-45, 87 Stat. 91, 93 (1973) (codified at 42 U.S.C. § 300 (2006)).

125. 42 U.S.C. § 300a-7(b).

126. Rachel Benson Gold, *Conscience Makes a Comeback in the Age of Managed Care*, 1 GUTTMACHER REP. ON PUB. POL'Y 1, 1-2 (1998), *available at* http://www.guttmacher.org/pubs/tgr/01/1/gr010101.pdf.

127. Omnibus Consolidated Rescissions & Appropriations Act of 1996, Pub. L. No. 104-134, sec. 515, § 245, 110 Stat. 1321, 1321-244-246 (codified as amended at 42 U.S.C. § 238n (2006)).

128. Consolidated Appropriations Act of 2008, Pub. L. No. 110-161, §508(d), 121 Stat. 1844, 2208-09.

funds from discriminating against health care providers who refuse to perform or teach services they find morally objectionable.[129]

More recently, HHS regulations issued in 2008, under the Bush Administration, were criticized for including a medically inaccurate definition of abortion that "conflated most modern contraceptives with abortion."[130] In 2011, the HHS rescinded and revised the 2008 regulations.[131] While the HHS still "supports clear and strong conscience protections for health care providers who are opposed to performing abortions,"[132] it "rescind[ed] those parts of the 2008 Final Rule that were unclear and overbroad in scope."[133]

III. IMPLICATIONS AND CONSEQUENCES OF THE MIXED MESSAGE

Prenatal genetic testing and abortion inevitably intersect, producing discordant effects as testing becomes more common and access to abortion becomes less available. This Part highlights common questions or themes in abortion and testing that do share common answers or meanings. In offering a sample of the inconsistencies in this complex area, we identify four issues in which the legal and policy aims of prenatal genetic testing and abortion diverge: what is considered reproductive health care; health care professionals' autonomy and discretion; the scope and purposes of information given to patients; and attitudes toward women's pregnancy decisions. In the short term, anti-abortion trends might overly influence policy debates about advances and innovations in prenatal diagnosis.

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129. Thaddeus Mason Pope, *Legal Briefing: Conscience Clauses and Conscientious Refusal*, 21 J. CLINICAL ETHICS 163, 163-80 (2010).

130. Adam Sonfield, *For the Record: Obama Administration Rescinds Most of Controversial "Conscience" Regulation*, 14 GUTTMACHER POL'Y REV. 24, 24 (2011), *available at* http://www.guttmacher.org/pubs/gpr/14/1/gpr140124.pdf.

131. Ensuring that the Dep't of Health & Hum. Serv. Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Fed. Law, 73 Fed. Reg. 78,072 (Dec. 19, 2008) (codified at 45 C.F.R. §§ 88.1-88.6 (2010) (repealed by §§88.2-88.5, amended by §88.6, amended and re-designated as §88.2 (2011)); Reg. for the Enforcement of Fed. Health Care Provider Conscience Protection Laws, 76 Fed. Reg. 9968 (Feb. 23, 2011) (codified as amended at 45 C.F.R. §§ 88.1-.886 (2011)).

132. Reg. for the Enforcement of Fed. Health Care Provider Conscience Protection Laws, 76 Fed. Reg. at 9969.

133. *Id.* The ACA reiterates protection for health professionals' refusals. *See supra* note 101 and accompanying text (noting the ACA's inclusion of a refusal right for physicians).

A. Testing and Abortion as Health Care

Testing is increasingly considered an integrated and ordinary part of prenatal care and abortion is decreasingly considered medical care at all. We identify three legal trends in this vein.

First, testing has not traditionally been a site of government regulation *because* it is a health care matter. Whether and when to test, like any other health care choice, is treated as a personal decision made by a patient in consultation with her physician. States for the most part do not mandate screening or testing; do not define what services are "medically necessary"; and do not, by and large, regulate what results patients may learn. For example, state or federal laws do not have consistent definitions of what constitutes a "severe" genetic disorder,[134] perhaps because of the wide range of clinical opinions and attendant fears of creating over and under inclusive definitions.[135] Abortion, however, has moved from being a private health care decision, left to the patient-physician relationship as envisioned by *Roe,* to services heavily regulated by the state.[136]

The ACA typifies the view that screening or testing is routine reproductive health care, and abortion is not. The ACA omits abortion as an essential benefit and requires segregation of all funds paid to state exchange plans that cover abortion, potentially reducing insurance coverage over the long term. Certain screening and testing services, however, will be paid for under the ACA while abortion will not. Thus, a woman may receive testing at no or low-cost, but will pay out-of-pocket for an abortion. Indeed, fifty-seven percent of U.S. women already pay out-of-pocket for abortion services, which can be expensive.[137] A termination at ten weeks of gestation can cost between $400 to $600 (whether through surgical or medical methods), with costs increasing to thousands of dollars as the pregnancy progresses in the second trimester.[138]

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134. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 339 (2002).

135. *See* Elyse Whitney Grant, Note, *Assessing the Constitutionality of Reproductive Technologies Regulation: A Bioethical Approach*, 61 HASTINGS L.J. 997, 1029 (2010) ("Certain genetic characteristics, such as a predisposition to breast cancer, straddle the line between therapeutic and non-therapeutic.").

136. B. Jessie Hill, *Abortion as Health Care*, 10 AM. J. BIOETHICS 48, 49 (2010).

137. RACHEL K. JONES ET AL., GUTTMACHER INST. CHARACTERISTICS OF U.S. ABORTION PATIENTS, 2008, at 1 (2010), *available at* http://www.guttmacher.org/pubs/US-Abortion-Patients.pdf.

138. For example, one clinic in Houston charges $420 for surgical and medical abortion before the eleventh week of pregnancy; $800 for abortion at twelve to thirteen weeks; $900 at

Second, this underscores the perception that abortion services, unlike testing services, have *no relation* to protecting women's physical or mental health.[139] *Roe v. Wade* required the state, if restricting abortion in the third trimester, to allow for the preservation of "the life or health of the mother."[140] *Casey*, although abandoning the trimester framework, reiterated that the state must protect women's health throughout pregnancy, including after viability.[141] Yet in *Gonzales v. Carhart*, the Supreme Court ignored evidence that intact D&E could be the safest abortion procedure available. In 2000, the Supreme Court struck down a state law banning intact D&Es, which mirrored the federal ban, in *Stenberg v. Carhart* because the Nebraska statute did not have an exception for women's health.[142] Seven years later, the Court upheld the federal analog because evidence of the effects on women's health cut both ways. The Court held that laws like the one in *Carhart* without exceptions to protect pregnant women's health are not unconstitutional per se, but subject to case-by-case analysis.[143] In the aftermath of *Carhart*, several states have passed or reinstated "partial birth abortion" bans[144] using language that is sometimes unclear as to which procedures or physician actions are illegal, increasing liability fears among providers.[145]

Third, and building from the previous two trends, abortion may become less recognizable as medical care after testing reveals serious fetal health problems.[146] We have argued that abortion has traditionally been one option that pregnant women could choose after learning of fetal anomaly. Indeed, a few state abortion laws explicitly recog-

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fourteen to fifteen weeks; and does not provide abortion past sixteen weeks. *Fees & Instructions*, HOUS. WOMEN'S CLINIC, http://www.houstonwomensclinic.com/fees.html (last visited Mar. 12, 2012).

139. In an early case, a federal district court struck down an Illinois law for vagueness that criminalized experimentation on a fetus unless experimentation was for therapeutic reasons. *See* Lifchez v. Hartigan, 735 F. Supp. 1361, 1363 (N.D. Ill. 1990) (holding that an impermissible consequence of the law was its potential bar to amniocentesis, which the court described as potentially experimental).

140. Roe v. Wade, 410 U.S. 113, 164 (1973) (permitting state regulation in the second trimester if "related to maternal health").

141. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 846, 873 (1992).

142. Stenberg v. Carhart, 530 U.S. 914, 929-30 (2000).

143. Gonzales v. Carhart, 550 U.S. 124, 158 (2007).

144. GUTTMACHER INST., STATE POLICIES IN BRIEF: BANS ON "PARTIAL-BIRTH" ABORTION (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_BPBA.pdf.

145. *See* LORI FREEDMAN, WILLING & UNABLE: DOCTORS' CONSTRAINTS IN ABORTION CARE 32 (2010).

146. *But see* Asch, *supra* note 134, at 340 (predicting exceptions for fetal anomaly in laws that restrict abortion before viability) (citing Martha Field, *Killing the Handicapped—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 110 (1993)).

nize severe fetal conditions as reasons or grounds for terminating a pregnancy after viability. Recently under attack, Texas permits post-viability abortion in the case of "severe and irreversible abnormality identified by reliable diagnostic procedures."[147] Maryland allows post-viability abortion if "the fetus is affected by genetic defect or serious deformity or abnormality."[148] Utah allows post-viability abortion of a fetus with a genetic disorder if two physicians agree in writing that the disorder is "uniformly diagnosable and uniformly lethal."[149]

As noted in Part I, by the time a prenatal diagnosis is confirmed, it may well be into the second trimester, at or after seventeen weeks.[150] Less than two percent of abortions occur in the second or third trimesters, and most of those terminations are for reason of fetal condition.[151] However, bans on methods like intact D&E and increasingly popular bans on terminations after twenty weeks will significantly affect the population of women who seek abortions after testing in their second and third trimesters.[152] Thus, at the time that most women confirm testing results, states are increasingly curtailing their abortion rights.

Non-invasive methods portend testing, and thus abortion, earlier in pregnancy or at least before twenty weeks of gestation.[153] However, if most women have their initial prenatal visit between eight and twelve weeks, followed by some combination of counseling, screening, and testing, there may be a short window of time to consider options before the twentieth week of pregnancy.[154] There is also a decreasing number of physicians willing to perform abortions at any point in pregnancy, but especially after the first trimester. Over the last sev-

147. TEX. HEALTH & SAFETY CODE § 170.002(b)(3) (2010). A bill introduced in 2011 sought to delete the fetal abnormality ground as well as remove impairment of mental health as a ground for post-viability abortion. H.R. 2988 § 170.002, 82d Leg., Reg Sess. (Tex. 2011).

148. MD. CODE ANN., HEALTH-GEN. § 20-209(b)(2)(ii) (LexisNexis 2011). Maryland's law allowing abortion on the ground of fetal abnormality was passed before *Roe v. Wade. See* MD. CRIM. CODE, Art. 43 §149E (1968) (renumbered by Acts 1970, chap. 736).

149. UTAH CODE ANN. § 76-7-302 (LexisNexis 2011).

150. *ACOG Practice Bulletin*, *supra* note 16, at 221.

151. Lena H. Sun, *From Abortion Provider to Activist,* WASH. POST, July 25, 2011, at A01.

152. Only 1.5% of abortions occur after twenty-weeks, and many are for medical emergencies. Eckholm, *supra* note 88, at MM13. Twelve percent of abortions are in the second trimester, and women who discover fetal abnormality are the majority of that group. Manian, *supra* note 108, at 228. After viability, at twenty-four or more weeks, most states, as noted, prohibit abortion unless the woman's health or life is at risk. *See supra* Part II.B (discussing post-viability restrictions).

153. Non-invasive testing can occur as early as five to seven weeks of pregnancy, with results by the tenth week of gestation. *See supra* Part I.A (discussing noninvasive methods for prenatal genetic testing).

154. Farrell et al., *supra* note 13, at 6.

eral decades, there has been a significant decrease in the number of abortion providers. Between the years of 1982 and 2005, the number of abortion providers in the United States declined from approximately 2,900 to 1,800.[155] Consequently, the number of counties in the United States with no abortion provider has increased: in 2005, eighty-seven percent of counties had no abortion provider, and ninety-seven percent of all non-metropolitan counties had no physician willing to perform terminations.[156] There are only a handful of physicians in the country that perform late-term abortions; women who seek their services after testing will likely travel hundreds of miles and spend thousands of dollars.[157]

As the experience of women like Claudia Crown Ades demonstrates, women pay the consequences of a health care system that refuses to recognize abortion as an important option for women and their families. In the next section, we consider similar trends in the treatment of the health care professionals.

B. The Integrity of the Medical Profession

At the intersection of prenatal genetic testing and abortion are contrasting visions of how much discretion health professionals may or should exercise. On the one hand, professional organizations like ACOG, non-governmental organizations like the NSCG, and policy makers call for better genetic counseling programs and better training for practitioners who counsel patients about genetic screening and testing options. Health care professionals report that they feel ill equipped to help patients fully understand what they may learn through screening and testing.[158] Moreover, pre-screening information is rarely accompanied with a detailed review of the advantages and disadvantages of post-screening options. Concerns about the inaccuracy or inadequacy of counseling, however, have not lead to closer state regulation but to proposals for increased availability of

155. Rachel K. Jones & Kathyrn Kooistra, *Abortion Incidence and Access to Services in the United States*, *2008*, 43 PERSP. SEXUAL & Reprod. Health 41, 41 (2011).

156. *Id.* at 41, 46. The number of abortion providers appears to have remained the same between 2005 and 2008. *Facts on Induced Abortion in the United States*, GUTTMACHER INST., http://www.guttmacher.org/pubs/fb_induced_abortion.html (last updated Aug. 2011). The decrease in the availability of providers is regional: outside of the Northeast and West, the number of abortions performed decreased from 12% or 9% between 2000 and 2005. Jones & Kooistra, *supra* note 156, at 44 (explaining that the number of abortions decreased 3% in the Northeast; 12% in the Midwest; 9% in the South; 12% in the West).

157. Sun, *supra* note 151.

158. King, *supra* note 44, at 24.

trained genetic counselors and a duty to refer patients to knowledgeable health care professionals.[159] Both suggestions for reform accord health care professionals broad discretion to counsel patients as appropriate to each patient. However, if those same obstetricians perform abortions, their discretion, as well as their motivations, will come under sharp state scrutiny.

Carhart reflects broader skepticism of physicians that provide abortions. Justice Ginsburg, writing in dissent, highlights that the majority opinion repeatedly refers to the obstetricians that perform intact D&Es as "abortion doctors."[160] Justice Kennedy, writing for the majority, argued that banning the procedure protects the physicians whose medical judgment the law curtails.[161] First, the Court suggested that the procedure is so gruesome that its performance cheapens the practice of medicine.[162] Second, the Court concluded that abortion providers cannot be trusted to exercise discretion in employing a health exception.[163] The Court stated that providers would potentially abuse the exception by claiming that all intact D&Es are performed to protect women's health.[164] The Court came to these conclusions despite evidence submitted by physicians and organizations like ACOG on the health benefits of intact D&Es versus other procedures for certain pregnancies.[165]

Concerns about health professional bias have arisen in the testing context too, but on a much different scale. Skeptics of the present trajectory of prenatal genetic testing question if physicians and genetic counselors overly focus on the medical complications of a child with the genetic condition.[166] In other words, a "powerful professional cul-

159. Amanda van den Heuvel et al., *Will the Introduction of Non-Invasive Prenatal Diagnostic Testing Erode Informed Choices? An Experimental Study of Health Care Professionals*, 78 PATIENT EDUC. COUNS. 24, 24 (2011).

160. Gonzales v. Carhart, 550 U.S. 124, 186-87 (2007).

161. Professor Sonia Suter argues that, in effect, *Carhart* "broadens the range of state interests that can justify limiting reproductive decisions," such as protecting the integrity of physicians, society as a whole, and the mental well being of women. Suter, *Carhart, supra* note 10, at 1519; *see also* Grant, *supra* note 135, at 1032 (questioning whether, post-*Carhart*, states could "ban [genetic testing technologies], citing to moral concerns").

162. *Carhart*, 550 U.S. at 160.

163. *See id.* at 159-60.

164. *Id.*

165. Brief of the American College of Obstetricians and Gynecologists as Amicus Curiae Supporting Respondents, Gonzales v. Carhart, 550 U.S. 124 (2007) (No. 05-380); Brief of American Medical Women's Association et al. as Amici Curiae Supporting Respondents, Gonzales v. Planned Parenthood Fed'n of America, Inc., 549 U.S. 807 (2006) (No. 05-1382).

166. Bagenstos, *supra* note 18, at 334-35, 440.

ture" problematizes and medicalizes all fetal anomalies.[167] As described by Professor Adrienne Asch, the "medical model" of disability envisions disability itself as the problem rather than the discrimination that persons with disabilities face, which misconceives the quality of life or life choices that persons with disabilities have or can make.[168] Wrongful birth and wrongful life claims typify these assumptions, which compensate parents for their "loss" in having a child with a disability.[169]

Wrongful birth claims highlight another contradiction in physicians' roles. The premise of the wrongful birth cause of action is that women would have aborted had they known about or understood the problems with their pregnancies. Liability in tort creates incentives for physicians to offer testing, and indeed obstetricians report increasing pressure to offer testing.[170] However, there is no liability for the same health care professional that does not offer abortion services or explain the advantages or disadvantages of electing abortion after testing. In fact, health professionals express hesitancy to discuss abortion options with their patients. For example, one study found that of physicians interviewed, most offer women testing but tell patients not to have an amniocentesis if they would not have an abortion.[171] Moreover, although obstetricians are often the parties that communicate what patients' options are post-testing,[172] a patient's primary obstetrician likely will not perform terminations. In 2009, only fourteen percent of obstetricians interviewed would or could provide abortion services.[173]

The hesitancy to discuss abortion may partly reflect states' heavy regulation of how health professionals communicate the risks of abortion. States have exacting record-keeping requirements for how physicians verify informed consent and states closely manage how physicians communicate information about abortion. For example, a

167. *Id.* at 451.

168. Asch, *supra* note 134, at 316.

169. *Id.* at 337.

170. If non-invasive testing can yield diagnostic results earlier in pregnancy with low risk to the mother, then the justifications that a health care professional might give for failing to offer women testing may seem less and less reasonable. *See* King, *supra* note 44, at 30.

171. *See* Robert Klitzman, Am I My Genes? Confronting Fate & Family Secrets in the Age of Genetic Testing 232 (2012) (discussing physician approaches to genetic counseling).

172. *See* Czerwinski et al., *supra* note 23, at 281.

173. Deborah A. Driscoll et al., *Screening for Down Syndrome: Changing Practice of Obstetricians*, 200 Am. J. Obstetrics & Gynecology 459.e1, 459.e5 (2009).

federal district court in Nebraska recently struck down a law imposing heavy penalties on physicians who fail to comply with vague and onerous informed consent standards.[174] Moreover, physicians interviewed believe a clinical practice that focuses mostly or largely on abortion will be "vilified" or seen as "evil" by their communities.[175] There is little reward, in terms of community public relations, in providing abortion services.[176]

Researcher Lori Freedman conducted a study of physicians willing and trained to provide abortion services, but who in practice do not.[177] Beginning by noting that only half of the obstetricians who *intend* to provide abortions in the course of their medical careers actually do,[178] Freedman describes how legal restrictions translate to the marginalization of abortion services. Although professional standards recommend training in abortion, federal intervention and the current operation of residency programs means that residents must "opt in" rather than opt out of training.[179] Managed care groups and physician practice groups routinely eliminate abortion from the care they provide. The costs of abortion care for obstetricians with diverse practices are steep because they do not develop the necessary technical skills or familiarity with regulations.[180] Freedman details how standalone abortion clinics can absorb the costs of regulation (waiting periods, licensing, and additional counseling) because they specialize.[181]

As testing and DNA sequencing evolve, states might seek to regulate genetic counselors and obstetricians as they do abortion providers, with laws, for example, that dictate ethics training, licensing, or facility standards in excess of normal requirements. A few states have already targeted abortion after testing. Tennessee, for example, for-

174. Planned Parenthood of the Heartland v. Heineman, 724 F. Supp. 2d 1025, 1043-45 (D. Neb. 2010) (citing the legislative intent of the Nebraska legislature, which the court held was rooted in protecting the fetus and deterring women from abortion).

175. FREEDMAN, *supra* note 146, at 93.

176. *Id.* at 104. Moreover, the murders of abortion providers at the hands of anti-abortion extremists foster a climate of fear. *See* Emily Bazelon, *The New Abortion Providers,* N.Y. TIMES, July 18, 2010, at MM30.

177. FREEDMAN, *supra* note 146, at 5.

178. *Id.* at 4.

179. *Id.* at 30-31 (describing the Coats amendment).

180. *Id.* at 103, 115.

181. *See id.* at 147. Freedman explains that physicians refer patients to clinics for convenience and, because of managed care rules, to save money. The network of clinics affiliated with Planned Parenthood, for example, can standardize abortion care in ways that minimize operation costs. *Id.* at 147.

bids testing offered in state programs for a condition that cannot be cured.[182] Missouri forbids state-sponsored genetic counseling programs from making a referral for an abortion unless the mother's life is in danger,[183] and Oklahoma makes it clear that genetic counselors are not required to mention abortion as a possible treatment option.[184]

Oklahoma's law illustrates conflicting expectations of health professionals that refuse to provide testing or abortion services. Physicians uncomfortable discussing prenatal genetic testing (either because of a lack of knowledge or because of testing generally) are urged to refer their patients to another physician or genetic counselor, and evidence suggests that they do refer patients to other professionals.[185] In abortion, however, state and federal refusal standards insulate health professionals from the possible repercussions of refusing to provide abortion services. Although ACOG and others also urge refusing physicians to refer patients to willing abortion providers[186] and to perform abortions in cases of medical emergency, obstetricians often do not in practice.[187] Given protections for physicians to refuse care based on moral or religious objection, obstetricians might object to certain aspects of genetic counseling if they believe their patients will choose to end pregnancies as a result.

C. Scope and Purposes of Information for Patients

What women receive in the way of information before testing and before abortion significantly differ, in terms of both the amount of information and the purpose of conveying the information.

There is a dearth of rules and regulations about what women *must* learn about their pregnancies through testing. As with other medical interventions, the expectation is that counseling should be non-directive and physicians' duties should fall on the side of disclosure.[188] Although there are efforts to standardize counseling policies

182. Tenn. Code Ann. § 68-5-504(a)(1) (2011).
183. Mo. Rev. Stat. § 191.320 (2011).
184. Okla. Stat. tit. 63, § 1-568 (2011).
185. American Cong. of Obstetricians & Gynecologists Comm. on Ethics, Committee Opinion: Informed Consent 7 (2009), *available at* http://www.acog.org/~/media/Committee%20Opinions/Committee%20on%20Ethics/co439.ashx?dmc=1&ts=20111227T1327130008.
186. *Id.*
187. *See* Huseina Sulaimanee, *Protecting the Right to Choose: Regulating Conscience Clauses in the Face of Moral Obligation*, 17 Cardozo J. L. & Gender 417, 425 (2011).
188. *See* American Medical Ass'n, *Opinion 8.082: Withholding Information from Patients*, *in* Code of Medical Ethics: Current Opinions with Annotations 253-54 (2008-09).

across the states, health insurance rules are perhaps the most significant influence on health professionals' behavior.[189] Laws do not require what women must know when deciding whether to screen or test. And pregnant women can learn a great deal about their future children. Whole gene sequencing promises to introduce parents to genetic information that not only predicts conditions like diabetes or mental illness but also reveals non-medical traits, such as eye color.[190]

A common complaint is that obstetricians do not communicate enough information about the risks and benefits of knowing testing results or the nature of the disorder at issue. Indeed, patients appear to have limited knowledge about the risks and benefits of prenatal genetic testing and screening.[191] There are, of course, limitations on what health professionals can reasonably know about a fetus from testing. Occurrence of a disorder may depend on a series of genetic interactions and environmental factors that determine whether and to what extent a condition manifests. Epigenetic factors, controlled by other genes and environmental influences, determine whether genes turn on or off.[192] It seems unlikely and perhaps unrealistic that obstetricians or genetic counselors could convey all the potential variations and possibilities about a child's future phenotype.[193] The problem of ambiguous testing results may become more acute as parents are able to learn genetic information that has unknown significance or genetic information that will affect a child later in life, such as carrying a recessive gene or a gene associated with late onset disorders like Huntington's disease.[194] The response to the confusion or anxiety resulting from testing, now and with future advances, is to call for clear and full communication of evidence-based information to patients.[195]

189. If testing becomes an everyday occurrence, health professionals may view counseling as a normal practice that does not require special training. Professor Jaime King cites a study of obstetricians' views on informed consent and non-invasive testing, which found that health care professionals are less likely to believe informed consent is as important for non-invasive testing as it is for amniocentesis or CVS. King, *supra* note 44, at 31.

190. Donley et al., *supra* note 31, at 4-5.

191. Studies suggest that patients generally confuse prenatal genetic testing and screening, and that their knowledge related to prenatal genetic testing and screening typically comes from friends or media. Vigdis Stefansdottir et al., *Effects of Knowledge, Education, and Experience on Acceptance of First Trimester Screening for Chromosomal Anomalies*, 89 ACTA OBSTETRICIA ET GYNECOLOGICA 931, 934, 936 (2010).

192. *Id.*

193. Chachkin, *supra* note 41, at 23-24.

194. Donley et al., *supra* note 31, at 4-5 (describing the information that whole genome sequencing can provide).

195. *Id.* at 7; *see also* Asch, *supra* note 134, at 340.

If states and the federal government have been largely absent in regulating information about testing, the opposite is true for abortion. As indicated in Part II, almost all states require communication about fetal development. Some states require that patients see pictures and renderings of fetuses at the various stages of development regardless of the point of gestation.[196] A handful of states mandate that women be told that fetuses might feel pain after a certain point in gestation.[197]

Mandatory ultrasound laws illustrate the level to which states control what patients seeking terminations should or must know.[198] Nine states require providers to offer patients the opportunity to view ultrasound images if an ultrasound would have already been conducted, and six states mandate that physicians give all patients opportunities to view ultrasound images regardless of whether the physician would typically conduct an ultrasound.[199] North Carolina, Oklahoma, and Texas have extreme iterations of these ultrasound laws.[200] The Oklahoma law, which a court has temporarily enjoined, mandates that physicians provide all women seeking abortion ultrasound images to view regardless of the patient's wishes. Likewise, Texas' and North Carolina's statutes require physicians to display and describe the sonograms of women seeking abortions, as well as play the sound of the fetal heartbeat, even if women ask not to see the images.[201] The

196. *See, e.g.*, IDAHO CODE ANN. § 18-609(2) (2012). Ian Vandewalker highlights that laws such as the Louisiana informed consent statute require patients undergoing early term abortions to view images of fetuses in the third trimester, without explanation of the difference between third and first trimester images. Vandewalker, *supra* note 109.

197. *See, e.g.*, IND. CODE § 16-34-2-1.1(a)(1)(G) (2011), *enjoined by* Planned Parenthood of Ind. v. Comm'r of Ind. State Dep't of Health, 794 F. Supp. 2d 892 (S.D. Ind. 2011) (holding that disclosing the likelihood of fetal pain offends the First Amendment rights of health professionals who only perform pre-viability abortions, and thus before fetuses can supposedly feel pain); MO. REV. STAT. 188.027(1)(5) (2011).

198. *See* Carol Sanger, *Seeing Is Believing: Mandatory Ultrasound & the Path to Protected Choice*, 56 UCLA L. REV. 351, 376 (2008).

199. GUTTMACHER INST., STATE POLICIES IN BRIEF: REQUIREMENTS FOR ULTRASOUND (2012), *available at* http://www.guttmacher.org/statecenter/spibs/spib_RFU.pdf (last visited Jan. 2012).

200. OKLA. STAT. tit. 63, § 1-738.3d(B) (2012) (stating that, at least one hour prior to abortion, a qualified medical professional shall describe the ultrasound image of the fetus, including a description of visible body parts and organs); H.R. 854, 2011 Leg., 405th Sess. (N.C. 2011) (providing that twenty-four hours prior to abortion, a qualified medical professional must personally or by telephone offer the patient an opportunity to view an ultrasound image of the fetus and listen to the heartbeat); H.R. 15, 82d Leg., 1st Spec. Sess. (Tex. 2011) (requiring, prior to an abortion, that a medical professional perform a sonogram, allow the patient to hear the heartbeat, and describe the sonogram to the patient).

201. Press Release, Ctr. for Reprod. Rts., Federal Judge Rejects Key Provisions of Texas Anti-Abortion Law (Aug. 30, 2011), http://reproductiverights.org/en/press-room/federal-judge-rejects-key-provisions-of-texas-anti-abortion-law:

North Carolina ultrasound law, for example, makes no exception for women who are victims of rape or incest.[202] Interestingly, in these three states, a woman could refuse an ultrasound for screening purposes, but not in the abortion context.

As noted, much of the informed consent standards for abortion communicate information about abortion's harmful effects on pregnant women. For example, most states mandate that patients receive information about the health risks of abortion, and a handful of states require communication of dubious long-term effects like breast cancer[203] or suicidal tendencies[204] or infertility.[205] Many of these laws require health professionals to inform women of the mental health or psychological problems they may suffer, such as depression, anxiety, and eating disorders, following abortion.[206] West Virginia, for example, requires practitioners to advise women that they may suffer from post-traumatic stress syndrome.[207]

In *Casey*,[208] the Supreme Court opened the door to these types of laws—laws that the Court in some instances held were biased or con-

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> [In August 2011,] U.S. District Judge Sam Sparks granted a preliminary injunction, ruling that doctors cannot be penalized if they violate the law's requirement that doctors show women seeking abortions their sonogram images, describe the images in detail, and play the sound of the fetal heartbeat if the women decline this information.

Id. However, the Fifth Circuit Court of Appeals recently lifted the injunction, holding that the district court erred in ruling that the physician-plaintiffs were likely to succeed in challenging the law's constitutionality. NPR, *Appeals Court Rules Texas May Enforce Abortion Law*, BOISE STATE PUB. RADIO (Jan. 10, 2011), http://www.boisestatepublicradio.org/2012/01/10/appeals-court-rules-texas-may-enforce-abortion-law/.

202. The Center for Reproductive Rights also won a temporary injunction against the North Carolina law. *See* Press Release, Ctr. for Reprod. Rts, Federal Court Blocks Demeaning North Carolina Ultrasound Law (Oct. 25, 2011), http://reproductiverights.org/en/press-room/federal-court-blocks-demeaning-north-carolina-ultrasound-law.

203. *See, e.g.*, ALASKA DEP'T OF HEALTH & SOC. SERVS., MAKING A DECISION ABOUT YOUR PREGNANCY: REFERENCES, STATE OF ALASKA HEALTH & SOCIAL SERVICES 6-7 (June 2010), http://www.hss.state.ak.us/dph/wcfh/informedconsent/assets/References.pdf (citing studies that support and negate the link between breast cancer and abortion).

204. However, the Eighth Circuit recently struck down a South Dakota law on First Amendment grounds for compelling physicians to discuss misleading risks of suicide. Planned Parenthood Minn., v. Rounds, 530 F.3d 724, 726, 733-37 (8th Cir. 2008).

205. *See, e.g.*, WIS. STAT. ANN. § 253.10(3)(c)(1)(f) (West 2011).

206. *See, e.g.*, Vandewalker, *supra* note 109, at 15 (citing laws in Michigan and West Virginia).

207. W. VA. DEP'T OF HEALTH & HUM. RES., INFORMATION ON FETAL DEVELOPMENT, ABORTION & ADOPTION 15 (2003), *available at* http://www.wvdhhr.org/wrtk/wrtkbooklet.pdf.

208. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 846 (1992). The Court held that states may limit abortion access so long as the state does not create an undue burden on the woman's choice to have an abortion, which, as applied, gives states much more discretion to restrict access to abortion and to extend protections for fetal life. *See* Linda J. Wharton et al., *Preserving the Core of* Roe*: Reflections on* Planned Parenthood v. Casey, 18 YALE J. L. & FEMINISM 317, 319-21 (2006).

veyed "irrelevant or inappropriate" information.[209] In previous cases, the Court expressed skepticism of informed consent laws that were plainly anti-abortion.[210] In *Thornburgh v. ACOG*, the Court held that states may not try to dissuade women from abortion or substitute the legislator's view of medically necessary information for the physician's.[211] Likewise, in *City of Akron v. Akron Center for Reproductive Health*, the Court struck down an informed consent law that related only negative side effects to patients.[212] However, in *Casey,* the Court upheld an informed consent law that imposed a waiting period, described the risks to the procedure and the alternatives to abortion and conveyed the gestational age of the fetus.[213] The Supreme Court held that laws may express a preference for childbirth over abortion so long as the counseling requirement does not impose an undue burden on women's decisions.[214] The Court reasoned that informed consent for abortion need not be treated similarly to other medical procedures.[215]

Although *Casey* maintained that information must be "truthful, nonmisleading" and "calculated to inform the women's free choice, not hinder,"[216] states have passed numerous laws that are arguably misleading and designed to hinder women's free choice. Decisions on the constitutionality of such laws have varied in the lower courts. Laws communicating information about the development of the fetus appear to be consistent with *Casey*.[217] For example, in *Planned Parenthood of Minnesota v. Rounds*, the Eighth Circuit upheld a

209. Manian, *supra* note 108, at 254.

210. *Id.* at 253.

211. Thornburg v. Amer. Coll. of Obstetricians & Gynecologists, 476 U.S. 747, 771-72 (1986) (striking down requirements for informed consent, record-keeping, and techniques designed to protect post-viability fetuses).

212. City of Akron v. Akron Ctr. for Reprod. Health, 462 U.S. 416, 452 (1983) (striking state hospitalization requirement for second trimester abortions).

213. 18 PA. CONS. STAT. § 3205 (2011).

214. Professor David Meyer has argued that *Casey* enacts a type of reasonableness requirement because, absent banning abortion altogether, the Court did not strike down state provisions that make abortion access logistically or financially difficult. David D. Meyer, *The Paradox of Family Privacy*, 53 VAND. L. REV. 527, 537-38 (2000).

215. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 882-83 (1992); *see also* Manian, *supra* note 108, at 253; Pamela Laufer-Ukeles, *Reproductive Choices and Informed Consent: Fetal Interests, Women's Identity and Relational Autonomy*, 37 AM. J.L. & MED. 567, 610-11 (2011) (indicating that abortion counseling departs from the liberal model of individual decision-making and is paternalistic as compared to other informed consent processes).

216. *Casey*, 505 U.S. at 882, 934. Courts have disagreed about the meaning of truthfulness in abortion informed consent laws. *See* Laufer-Ukeles, *supra* note 216, at 614 (contrasting cases in which courts found counseling information biased or not biased).

217. *See Casey*, 505 U.S. at 882.

South Dakota law that required providers to inform patients that they were about to terminate "the life of a whole separate, unique, living human being . . . , [and] that the pregnant woman has an existing relationship with that unborn human being."[218]

As in regulating the physician's role, legislatures seek to reduce the information that a woman can learn through testing *only if* the results might lead to abortion. Oklahoma permits health care professionals to withhold information learned from sonogram about fetal conditions. The statute also prohibits parents from suing physicians in wrongful birth actions if the physician withheld information that may have encouraged the parents to terminate pregnancies.[219]

This legislative example illustrates the different purposes of giving patients information in testing versus abortion. For testing, and as dictated by most informed consent standards, physicians generally must provide patients with enough information to weigh the risks and benefits of testing.[220] However, in abortion, information may attempt to dissuade the woman from the termination or to express the state's animus toward abortion.

In theory, testing for genetic disorders should be accompanied with information that is tailored to the patient and her particular needs. In practice, there is wide variation in how communication between the patient and health professional takes place. However, if a woman elects abortion after testing, she will encounter a system with different goals and a different approach: counseling of and information to women is not contextual or individualized. Informed consent rules for abortion treat all patients the same.[221] Scott Woodcock, in advocating a more nuanced, contextualized approach to abortion counseling, notes that "there is no single, uniform 'pregnant woman' perspective to which we can appeal in order to set a fixed policy that

218. Planned Parenthood Minn. v. Rounds, 530 F.3d 724, 726 (8th Cir. 2008). *But see* Doe v. Planned Parenthood Chicago Area, 956 N.E.2d 564, 572 (Ill. App. Ct. 2011) (holding that physicians have no common law duty to inform patients that abortion "kills" a human being); Acuna v. Turkish, 930 A.2d 416, 428 (N.J. 2007) (holding that a physician is not liable for failing to disclose that a fetus is a "complete, separate, unique and irreplaceable human being").

219. OKLA. STAT. ANN. tit. 63, § 1-738.2 (West 2011); OKLA. STAT. ANN. tit. 63, § 1-741.12 (West 2011). The Arizona Senate has recently passed a similar bill. Assoc. Press, *Senate Approves Bill on 'Wrongful Births'*, AZ. CAP. TIMES, Mar. 6, 2012, *available at* http://azcapitoltimes.com/news/2012/03/06/senate-approves-bill-on-wrongful-births/.

220. King, *supra* note 44, at 30-31.

221. Scott Woodcock, *Abortion Counseling & the Informed Consent Dilemma*, 25 BIOETHICS 495, 502-03 (2010) ("The best strategy is instead to provide the education, time and background training necessary to connect meaningfully with each patient and to help her to make an appropriately informed decision.").

will facilitate the autonomous decision-making of patients considering abortion."[222] The next section explores what the current approach suggests about pregnant women's judgment and ability to make decisions.

D. Pregnant Women and Decision-Making

At the heart of testing and abortion are deeply engrained perceptions about women's roles as decision-makers and women's attitudes toward their pregnancy options. The responsible pregnant woman wants information about her pregnancy. Yet, the law expects women as patients to make independent decisions about testing, but not abortion. As the last section demonstrated, in abortion, laws detail what women should know and how their decisions should be made. In testing, there is very little regulation of what decisions women can make before and after testing, although women may feel intense social pressure to test and to uncover potential problems with their pregnancies.

Several studies document the anxiety pregnant women can feel after learning test results. And, indeed, many women express uncertainty about whether or not to screen (and then to test) in the first place. For example, research shows that a positive screen causes some women to decline screening in subsequent pregnancies, and women express varying levels of anxiety between learning results and genetic counseling appointments.[223] Another study showed that women are uncertain about the risks and benefits of screening, which are "layered on to more general baseline concerns" about their pregnancies.[224] Some women do not elect screening or testing if they would not terminate the pregnancy.[225] This suggests that women begin conversations about screening by discussing "downstream options:" the choice of potentially ending a pregnancy is "an ethical part of the whole decision about whether or not to take any of these tests."[226] Increased screening or testing may not necessarily correspond with higher abortion rates.[227]

222. *Id.* at 499 (noting the powerful social influences on women to bear and care for children).

223. Czerwinski et al., *supra* note 23, at 280.

224. Farrell et al., *supra* note 13, at 4.

225. *See* Norton, *supra* note 23, at 158.

226. Farrell et al., *supra* note 13, at 5 (citing the statement of a study participant).

227. Driscoll et al., *supra* note 174, at 459.e4. *But see* Benn & Chapman, *supra* note 36, at 131 (describing the role of non-invasive testing as potentially resulting in increased abortion).

Thus, proposals in the testing context seek to manage anxiety in ways that will differ for each woman. But anxiety in abortion decisions invites states to regulate decision-making more closely—to "protect" women from the psychological consequences of abortion. For example, in *Carhart*, the Court held that there was a legitimate state interest in protecting the emotional health of women who may come to regret their decision.[228] In making this assumption, the Court opined that some women inevitably regret their decisions: "[w]hile we find no reliable data to measure the phenomenon, it seems unexceptionable to conclude that some women come to regret their choice to abort the infant life they once created and sustained."[229]

Policy following the introduction of non-invasive prenatal genetic testing could reflect the concern that women receiving genetic test results are in difficult decisional spaces and need more information about their pregnancies. Professor Samuel Bagenstos has written about how the jurisprudence on informed consent for abortion could be the place where states seek to limit any social pressures women may feel to abort after learning test results.[230] States could also try to limit women's access to particular genetic information until after viability. For example, states might restrict a woman's reasons for abortion, particularly for terminations based on non-medically relevant fetal traits.[231] Pennsylvania and Illinois already forbid sex selective abortion, and Arizona and Oklahoma recently passed laws restricting abortion because of the sex (and, in Arizona, race) of the fetus.[232]

228. Suter, *Carhart*, *supra* note 10, at 1576-77.

229. Gonzalez v. Carhart, 550 U.S. 124, 159 (2007); *cf. id*. at 183 n.7 (Ginsburg, J., dissenting) (stating that while abortion may be a "painfully difficult decision," having an abortion is no more harmful in the long run than having a child). In a recent Nebraska case, a federal district court found that a law creating substantial penalties for physicians who did not comply with onerous, "impossible to meet" rules *presumes* women will experience regret. Planned Parenthood of the Heartland v. Heineman, 724 F. Supp. 2d 1025, 1045 (D. Neb. 2010) ("[The law] provides the remorseful woman and her lawyer with a very substantial financial incentive to initiate such litigation, whether or not she truly does regret her decision to obtain an abortion—her regret is *presumed*."). *But see* Planned Parenthood of Middle Tenn. v. Sundquist, 38 S.W.3d 1, 23 (Tenn. 2000) (noting that expert opinion suggests women that "seriously contemplated their [abortion] decision before making their appointment").

230. Bagenstos, *supra* note 18, at 452.

231. Suter, *Carhart*, *supra* note 10, at 1516-17.

232. 720 ILL. COMP. STAT. ANN. 510/6-(8) (West 2011); OKLA. STAT. tit. 63, § 1-731.2(b) (2011); H.B. 2443, 50th Leg., 1st Reg. Sess. (Ariz. 2011); 18 PA. CONS. STAT. ANN. § 3204(c) (West 2000) ("No abortion which is sought solely because of the sex of the unborn child shall be deemed a necessary abortion."); *see also* Sunita Puri, *"I Know It's a Girl and I Need Your Help to Get It Out of Me*," SLATE (Aug. 2, 2011, 2:39 PM), http://www.slate.com/articles/double_x/doublex/2011/08/i_know_its_a_girl_and_i_need_your_help_to_get_it_out_of_me.html (discussing providers' conflicts with patients over sex selection).

Laws banning sex selective abortion raise questions as to what are permissible restrictions on a woman's reasons for abortion, especially before viability. Could a state forbid abortion based on genetic information that is medically relevant, but does not put the mother's physical health or life at risk?[233] Or, could states prohibit terminations based on genetic information about late onset disorders, such as Alzheimer's disease?[234]

These questions would be difficult for anyone to answer without baseline principles to help navigate the ethical complexities of abortion and testing. And the Unites States is not alone in meting out these debates.[235] For example, the Council of Europe issued a Recommendation on Prenatal Genetic Screening, Prenatal Genetic Diagnosis, and Associated Genetic Counseling that sets out standards for non-directive counseling for all options prior and after testing, including abortion; the central role of the physician in carrying out screening and testing "adapted to the person's circumstances"; and testing focused on the detection of serious risk. Likewise, the International Federation of Gynecology and Obstetrics (FIGO) frames abortion as a health care choice after testing, urging that terminations "must be offered" if a woman submits to testing which uncovers "a severe untreatable fetal disease or malformation."[236]

More recently, the European Court of Human Rights (ECtHR) highlighted the approach of the Recommendation and FIGO in the 2011 case, *R.R. v. Poland*.[237] In *R.R. v. Poland*, the ECtHR held that Poland was in violation of the European Convention on Human Rights for denying a woman prenatal genetic testing, which would

233. *See* Suter, *Prenatal Testing*, *supra* note 15, at 255-56.

234. *Id.* at 266.

235. Greely, *supra* note 7, at 291 (noting consortiums organized by the European Union and foundations in the United Kingdom have been studying the medical and ethical issues of non-invasive testing for years). There also appears to be growing international consensus on serious fetal anomaly as a ground for abortion. *See* Christina Zampas & Jamie M. Gher, *Abortion as a Human Right—International and Regional Standards*, 8 HUM. RTS. L. REV. 249, 284-86 (2008). For example, the African Protocol on the Rights of Women to African Charter explicitly supports women's right to abortion if "the continued pregnancy endangers the . . . life of . . . the foetus." *Id.* at 250, 286 (citing Article 14.2(c) of the Protocol).

236. FED'N OF GYNECOLOGY & OBSTETRICS COMM. FOR THE STUDY OF ETHICAL ASPECTS ON HUMAN REPROD., RECOMMENDATIONS ON ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY 76 (2009), *available at* http://www.figo.org/files/figo-corp/Ethical%20Issues%20-%20English.pdf. FIGO is currently composed of 124 professional societies of obstetricians and gynecologists worldwide, including ACOG. FIGO recognizes that many countries do not allow abortion on request but recognize a legal ground for fetal malformation or disorder. *About FIGO*, FIGO, http://www.figo.org/about (last visited Mar. 20, 2012).

237. R.R. v. Poland, 27617/04 Eur. Ct. H.R. at 12-13, 20 (2011), *available at* http://cmiskp.echr.coe.int/tkp197/search.asp?skin=hudoc-en.

have allowed her to decide whether or not to seek a legal abortion.[238] The ECtHR noted that non-directive genetic counseling should leave the woman free to make her own decision.[239] Moreover, the ECtHR held that testing should be "made as widely available as possible," and abortion decisions should be "discouraged only if the disorder is treatable and will not necessarily affect the future quality of life."[240] *RR v. Poland* illustrates an approach concerned with the effects of having the child on the woman and her family, as well as the ethical questions of the conditions under which to terminate a pregnancy.[241] The decision is not necessarily pro-abortion or pro-testing: rather, it attempts to facilitate decision-making suited to the individual's needs, guided by respect for women, parents, and potential life.

By contrast, there has been no concerted effort in the United States to wrestle with these questions, despite calls for guidance from federal agencies and professional organizations.[242] Almost forty years after *Roe* was decided, there are few guideposts or standards in this country to weigh these competing and mixed messages.

CONCLUSION

This Article began by noting that a catalyst for change in U.S. abortion law was the health needs of women who discovered problems with their pregnancies. It is critical to women's health and well-being that abortion is part of a continuum of health care. Increased prenatal testing should be accompanied by policies that recognize abortion as a medical option for some women. Without a robust dialogue about the mixed messages at the intersection of abortion and testing, the current stigma and opposition to abortion may dominate

238. *See id.* at 5, 33. Polish law provided, "[t]he State and local administration shall ensure unimpeded access to prenatal information and testing, in particular in cases of increased risk or suspicion of a genetic disorder or development problem or of an incurable life-threatening ailment." 1993 Family Planning (Protection of the Human Foetus & Conditions Permitting Pregnancy Termination) Act, Official Journal of the Republic of Poland no. 17, item 78, § 2(a) (1993). A physician working in a hospital may perform an abortion pre-viability where "[p]renatal tests or other medical findings indicate a high risk that the fetus will be severely and irreversibly damaged or suffering [sic] from an incurable life-threatening ailment." *Id.* § 4(a).

239. Comm. of Ministers of the Council of Europe, *Recommendation No. R (90) 13 on Prenatal Genetic Screening, Prenatal Genetic Diagnosis & Associated Genetic Counseling*, 41 INT'L DIG. OF HEALTH LEGIS. 615 (1990).

240. Int'l Fed'n of Gynecology & Obstetrics Ethics Comm., *Ethical Aspects of Termination of Pregnancy Following Prenatal Diagnosis*, 39 INT'L J. GYNECOLOGY & OBSTETRICS 1, 1-2 (1992).

241. *Id.*

242. Benn & Chapman, *supra* note 36, at 130.

the national conversation. Indeed, former presidential candidate, Rick Santorum, recently promoted his anti-abortion beliefs by arguing that the ACA, in providing funding for prenatal genetic screening and testing, "ends up in more abortions."[243] But the conversation cannot and should not be that conclusive. Law and practice need to conceptualize testing and abortion as interconnected health care choices that implicate complex and contextual considerations for pregnant women.

243. Rebecca Kaplan, *Santorum Attacks Obama on Prenatal Screening*, CBSNEWS (Feb. 18, 2012), http://www.cbsnews.com/8301-503544_162-57380887-503544/santorum-attacks-obama-on-prenatal-screening/?tag=contentMain;contentBody.