

Fostering Informed Choice: Alleviating the Trauma of Genetic Abortions

Bret D. Asbury

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ARTICLES

FOSTERING INFORMED CHOICE: ALLEVIATING THE TRAUMA OF GENETIC ABORTIONS

*Bret D. Asbury**

Each year, thousands of pregnant women learn of fetal abnormalities through prenatal genetic analysis. This discovery—made after a woman has initially declined to exercise her right to abort an unwanted pregnancy—raises the difficult and heart-wrenching question of whether to terminate on genetic grounds. Women considering a genetic abortion rely on information and support from health care providers to assist them in making their choice. Though intended to be objective and nondirective, the support women receive frequently provides them with incomplete and incomprehensible information having the effect of encouraging them to abort genetically anomalous fetuses. As a result, genetic terminations—which cause severe and long-standing psychological impacts such as pathological grief, depression and post-traumatic stress—are often the result of something other than a fully informed choice.

Congress and eleven states have recognized the importance of better informing choice by passing legislation aimed at providing clearer and more balanced information to expectant mothers learning of fetal genetic abnormalities. But existing legislative remedies do not adequately address this problem, and this inadequacy will become more pronounced in future years as increases in access to prenatal genetic analysis further stretch the capabilities of the available support services. This Article describes the unique characteristics of terminations for a fetal abnormality, their troubling and persistent psychological impacts, and the reasons why they will become more common in future years. It then offers proposals for how to reconfigure the prenatal genetic counseling landscape in order to reduce the incidence of genetic terminations based on incomplete or misleading information, thereby alleviating their

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distinct psychological costs. Its overall objective is to ensure that women learning of prenatal genetic abnormalities have access to complete and comprehensible information prior to making their decision and adequate support whether or not they choose to terminate.

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INTRODUCTION

But I cannot help thinking of the other possibility: that it was alright after all. Yes, that really kills me sometimes. We might have had a child now, and maybe even a healthy child at that!¹

—Father Number 14

Though nearly nine of ten abortions in the United States occur within the first twelve weeks of pregnancy,² among the 11% occurring

¹ Marijke J. Korenromp et al., *Termination of Pregnancy on Genetic Grounds; Coping with Grieving*, 13 J. PSYCHOSOMATIC OBSTETRICS & GYNECOLOGY 93, 98 (1992).

² GUTTMACHER INSTITUTE, FACTS ABOUT INDUCED ABORTION IN THE UNITED STATES 2 (2014), www.guttmacher.org/pubs/fb_induced_abortion.pdf (noting that 1/3 of abortions occur within the first six weeks of gestation and 89% occur within the first twelve). These terminations can arise out of any number of circumstances. The Guttmacher Institute describes some

later there exists a small subset which raise unique and vexing ethical concerns: abortions of initially wanted pregnancies based on fetal abnormalities discovered during prenatal genetic analysis.³ The range of what constitutes an abnormality serving as the basis for a genetic termination is considerable. On one extreme are conditions such as anencephaly, in which a fetus never develops certain portions of its brain and skull and in most cases dies during pregnancy or soon after birth. On the other, conditions such as hemophilia and surgically repairable abdominal wall defects such as omphalocele and gastroschisis fall into this category. In between are a number of conditions with varying presentations and a wide range of potential quality-of-life outcomes, such as cystic fibrosis, spina bifida, and Trisomy 21 (Down syndrome).

A pregnant woman learning of a fetal abnormality must, at a time of unique and unanticipated stress and anxiety, develop enough of an understanding of the potential challenges she, her child, and her family will be forced to endure in order to make an informed decision about whether to bring her pregnancy to term.⁴ It is here that prenatal genetic counseling plays a crucial role, assisting expectant mothers in making sense of their test results and deciding how to proceed. Unfortunately, genetic counseling is failing many women, leading to underinformed terminations that result in unique and longstanding psychological impacts such as pathological grief, depression, and post-traumatic stress.

Though the core aspiration of modern genetic counseling is “nondirectiveness”—meaning providing unbiased genetic information rather than guiding expectant mothers to proceed or terminate their pregnancy⁵—numerous studies have shown that real-life practice diverges

of the reasons as follows: “The reasons women give for having an abortion underscore their understanding of the responsibilities of parenthood and family life. Three-fourths of women cite concern for or responsibility to other individuals; three-fourths say they cannot afford a child; three-fourths say that having a baby would interfere with work, school or the ability to care for dependents; and half say they do not want to be a single parent or are having problems with their husband or partner.” *Id.* at 1 (citing Lawrence B. Finer et al., *Reasons U.S. Women Have Abortions: Quantitative and Qualitative Perspectives*, 37 PERSPECTIVES ON SEXUAL & REPRODUCTIVE HEALTH 110, 112 (2005)).

³ This Article employs the term “genetic analysis” as a shorthand for prenatal genetic screening, which assesses the likelihood of a fetal abnormality through a maternal blood test, and prenatal genetic testing, which confirms certain abnormalities most often through the collection of amniotic fluid or placental tissue. This distinction is discussed in greater detail in Part I.

⁴ To be sure, personal attitudes toward abortion play a significant role in the difficulty of this decision. For mothers who would choose to bring their fetus to term under any circumstance, a genetic abnormality serves only as a basis for learning more about their fetus’s condition and preparing for raising a child with special needs. For those who would consider having an abortion under some circumstances, however, the choice can be extraordinarily difficult.

⁵ See, e.g., Patricia L. Devers et al., *Noninvasive Prenatal Testing/Noninvasive Prenatal Diagnosis: The Position of the National Society of Genetic Counselors*, 22 J. GENETIC COUNSELING 291, 292 (2013) (“NSCG firmly believes that reproductive decisions should be made in

significantly from this objective.⁶ Expectant mothers who undergo genetic counseling frequently feel that they receive incomplete or one-sided information that stresses the negative aspects of genetic findings rather than the unknown or positive aspects.⁷ As a result, women frequently come away from counseling sessions with inaccurately grim prognoses for their future child's quality-of-life, which in turn makes them more likely to abort on genetic grounds, as most of them do. In this way genetic counseling is all too often anything but nondirective, and critiques acknowledging that the nondirectiveness aspiration remains elusive have emerged from both outside and within the field.⁸

Genetic terminations occupy a unique space between traditional abortions and the generally more traumatic outcome of stillbirth.⁹ Having already chosen to bring a fetus to term—and having often begun to show and share the joyous news with friends and loved ones—pregnant women learning of a fetal abnormality find themselves in the difficult position of revisiting this decision at a much later stage, when their expectations and aspirations for their unborn child have begun to develop more fully. It should come as no surprise that the subsequent experience of women who exercise their right to traditional abortions differs markedly from those who terminate on genetic grounds. Whereas the former experience no increased risk of mental health problems following a sin-

the context of unbiased and comprehensive information, free from discrimination or coercion”) (citing *Position Statement: Reproductive Freedom*, NAT'L SOC'Y OF GENETIC COUNSELORS (June 1, 2010), <http://nsgc.org/p/bl/et/blogid=47&blogaid=35>).

⁶ See *infra* Part I.B for a discussion of these studies and the nature of genetic counseling in practice more generally.

⁷ See, e.g., Christy D. Roberts et al., *The Role of Genetic Counseling in the Elective Termination of Pregnancies Involving Fetuses with Disabilities*, 36 J. SPECIAL EDUC. 48, 53 (2002) (finding that 87% of women in their cohort “indicated that genetic counseling did not give them information about future-quality-of-life issues for a child with a disability” and 86.2% “indicated that the genetic counselor did not provide them with both positive and negative aspects of giving birth to a child with a disability”); Anne C. Madeo et al., *The Relationship Between the Genetic Counseling Profession and the Disability Community: A Commentary*, 155 AM. J. MED. GENETICS PART A 1777, 1779 (2011) (describing a Down syndrome study finding that while 95% of genetic counselors discussed its underlying biomedical aspects, just 26% described its many well-documented and positive “social aspects of life” and finding that among the genetic counseling encounters analyzed, “86% mentioned pregnancy termination, 37% continuation of pregnancy, and 13% adoption”) (citing E. Farrelly et al., *Genetic Counselors and Prenatal Testing: Where is the Discussion About Disability?*, 19 J. GENETIC COUNSELING 671, 671 (2010)).

⁸ See, e.g., Madeo et al., *supra* note 7, at 1777–80 (discussing some of the tensions between the attitudes and practices of genetic counselors and the perspectives of disability and advocacy communities).

⁹ Korenromp et al., *supra* note 1, at 95 (“Termination of pregnancy on genetic grounds is different from abortion in that it is an initially wanted pregnancy. It differs from stillbirth because the parents themselves have to decide whether the child will live or die.”).

gle abortion,¹⁰ the latter often suffer significant negative psychological effects.¹¹ One study has gone so far as to conclude that “termination of an abnormal pregnancy in the second trimester should be regarded as no less serious than a stillbirth and . . . acute grief by the parents must be expected.”¹² The lasting emotional and psychological impact of genetic terminations—on not just the women carrying these fetuses, but also on their partners and living children—evidences the crucial importance of prenatal genetic counseling and underscores the extent to which it is currently failing pregnant women.

Recognizing the national significance of these issues, Congress passed the Prenatally and Postnatally Diagnosed Conditions Awareness Act.¹³ Co-sponsored by anti-abortion crusader Sen. Sam Brownback (R-Kan.) and pro-choice and disability-rights advocate Sen. Ted Kennedy (D-Mass.), the Act was signed into law by President Bush in October of 2008. Though noble in its aims at addressing a number of the deficiencies in genetic counseling described in this Article,¹⁴ the Act has been and remains grossly underfunded and has yet to have any meaningful impact. More recently, there has been a flurry of activity at the state level seeking to address the deficiencies of genetic counseling. To date, eleven states have passed legislation aimed at providing additional information to women learning of fetal genetic abnormalities, nine of which have done so since 2012.¹⁵ Though this state action has the potential to fill some of the gaps in genetic counseling highlighted but not addressed by the federal Act, such legislation is limited both geographically and

¹⁰ See BRENDA MAJOR ET AL., AM. PSYCHOL. ASS'N TASK FORCE ON MENTAL HEALTH AND ABORTION, REPORT OF THE APA TASK FORCE ON MENTAL HEALTH AND ABORTION 91 (2008), www.apa.org/pi/wpo/mental-health-abortion-report.pdf.

¹¹ For a detailed discussion of the emotional and psychological impact of genetic terminations, see *infra* Part II.

¹² S. H. Elder & K. M. Laurence, *The Impact of Supportive Intervention After Second Trimester Termination of Pregnancy for Fetal Abnormality*, 11 *PRENATAL DIAGNOSIS* 47, 53 (1991); see also Charles H. Zeanah et al., *Do Women Grieve After Terminating Pregnancies Because of Fetal Abnormalities? A Controlled Investigation*, 82 *OBSTETRICS & GYNECOLOGY* 270, 274 (1993) (“The results of the current investigation suggest that the psychological adaptation of women following prenatal diagnosis and termination of pregnancy is more like that of women who experience a spontaneous perinatal loss, with whom they share a wanted pregnancy, than that of women who undergo elective termination, with whom they share a voluntary decision to terminate.”).

¹³ Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110–374, 122 Stat. 4051 (2008).

¹⁴ See *id.* at 4051 (describing the purposes of the Act as being to “provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes,” “strengthen existing networks of support” for families facing prenatally and postnatally diagnosed conditions, and “ensure that patients receive up-to-date, evidence-based information about the accuracy” of tests diagnosing Down syndrome and other genetic conditions).

¹⁵ See *infra* Part II.

with respect to the conditions addressed, and it does nothing to reform the status quo of prenatal genetic counseling as a whole.

Moreover, though prenatal genetic counseling currently plays a meaningful role in only a tiny fraction of pregnancies, the scale and scope of the psychological challenges borne out of its deficiencies will increase manifold in the upcoming years for two reasons. First, by expanding the number of women covered by Medicaid, establishing baseline coverage requirements for preventive care for women, and categorizing maternity and newborn care as “essential benefits” that must be covered by all insurers, the Patient Protection and Affordable Care Act (ACA)¹⁶ will grant millions of women newfound access to low-cost or free genetic screening, testing, or both.¹⁷ Second, whereas the most accurate forms of genetic testing most commonly employed today are invasive and potentially harmful to the fetus, pinpoint accurate, risk-free Noninvasive Prenatal Diagnosis (NIPD) has arrived and is being rapidly deployed across the country. Taken together, these two changes—free or low-cost prenatal genetic screening for a broader population of women and advances in NIPD—could result in an increase in prenatal genetic testing from less than 100,000 per year to over 3,000,000.¹⁸

Seeking to address prenatal genetic counseling’s current shortcomings, the failure of legislative efforts to address them, the profound psychological impacts of genetic terminations, and the imminent explosion in the demand for prenatal genetic counseling, this Article argues for a radical shift in how healthcare providers treat women learning of prenatal genetic abnormalities. Due to their unique circumstances and attendant psychological risks, all such women should be presented with balanced, up-to-date, and accurate information regarding the implications of bringing their fetuses to term and have easy access to adequate support services whether or not they proceed with their pregnancies. As will be shown below, women currently have access to nothing of this sort.

This Article proceeds in five parts. Part I provides an overview of the current role of prenatal genetic screening, testing, and counseling in pregnancy and describes the challenges inherent in deciding whether to bring a genetically anomalous fetus to term. It then offers a closer examination of prenatal genetic counseling, showing that it is frequently directive in practice, nudging women toward aborting genetically anomalous fetuses without complete information. Part II describes the unique and troubling traumatic psychological impacts that genetic abortions can

¹⁶ Patient Protection and Affordable Care Act, Pub. L. No. 111–448, 124 Stat. 119 (2010).

¹⁷ See *infra* Part IV.A.

¹⁸ See Henry T. Greely, *Get Ready for the Flood of Fetal Gene Screening*, 469 NATURE 289, 290 (2011).

have on expectant mothers and their families, identifying elevated rates of grief, depression, and post-traumatic stress as the primary indicators. Part III discusses federal and state legislative responses to prenatal genetic counseling's incomplete and at times directive presentation of information and describes their inadequacies. These inadequacies will become increasingly salient in future years due to the emerging growth in the need for prenatal genetic counseling ushered in by the Affordable Care Act's expansion of access to prenatal genetic analysis and the rapidly evolving field of Noninvasive Prenatal Diagnosis, which are discussed in Part IV. Part V offers suggestions for how to address the oncoming explosion in the need for widespread, improved genetic counseling. Using the Prenatally and Postnatally Diagnosed Conditions Awareness Act as a starting point, this Part proposes model pro-information legislation and describes how medical professionals should treat expectant mothers (and their partners) learning of a fetal abnormality from the outset through their decision whether or not to terminate.

I. THE PRENATAL GENETIC LANDSCAPE

Because just one in sixteen babies in the United States is born with a birth defect,¹⁹ the majority of parents (to say nothing of the population as a whole) are largely unfamiliar with the significant role that prenatal genetic analysis and counseling play in determining which babies are born and which fetuses are terminated. But for any pregnant woman who has come face-to-face with an anomalous genetic screening or test result, the role of these fledgling fields in determining her reproductive choices cannot be overstated. Due to the life-altering impact of the decision to terminate or bring to term a genetically anomalous fetus, an exploration of the scaffolding currently surrounding that choice is essential prior to proceeding to discuss how it can be improved. This Part provides an overview of prenatal genetic analysis and counseling in operation and offers a glimpse into the anguish expectant mothers experience upon learning of a fetal genetic anomaly. It then examines how prenatal genetic counseling falls short in providing expectant mothers with much of the information they need in deciding whether to terminate and explains why nondirectiveness remains an elusive objective.

A. *Prenatal Screening, Testing, and Counseling*

Being told that one's fetus has an actual or potential genetic abnormality produces a rush of fear, heartache, and concern. Having chosen to keep rather than abort their pregnancies at the outset, women receive this sad news as they are preparing to be mothers, and few of them anticipate

¹⁹ TROY DUSTER, *BACKDOOR TO EUGENICS* 39 (2d ed. 2003).

that the child they are carrying will be anything other than normal and healthy. Indeed, one can safely assume that the vast majority of these women have never considered any of the ethical, financial, and psychological challenges that carrying a genetically anomalous fetus to term will entail, and many have never entertained the possibility of having an abortion. Yet suddenly they must.

Some women learn of a potential fetal abnormality through first-trimester serum screening, a test of the mother's blood that usually takes place between the eleventh and thirteenth weeks of pregnancy.²⁰ Others become aware of a potential abnormality during the more customary second-trimester quad or triple serum screen, which takes place after the fourteenth week of pregnancy. In either case, the serum screening does not provide a definitive diagnosis, but rather an indication that there is an elevated likelihood of a genetic abnormality, that there might be a problem.²¹

Nonetheless, a "screen-positive" result can be difficult to bear. Learning through serum screening that one's fetus has, for example, an "elevated risk" of Down syndrome is horrifying, despite the fact that out of any 1000 pregnancies as many as 40 can screen positive for this condition, and just one of these 40 will actually have Down syndrome.²² Though far from definitive, an indication of elevated risk through serum screening hits mothers hard, as it forces them for the first time to consider that their fetus might be born disabled, or could possibly have a condition that is incompatible with life.

Where an elevated risk is present, pregnant women most often undergo a more invasive test for confirmation: chorionic villus sampling (CVS) of the placenta during the first trimester or amniocentesis (extraction of amniotic fluid through a needle inserted into the mother's abdomen) in the second. Even deciding whether to undergo CVS or amniocentesis can be taxing because both procedures are "invasive," meaning that they require collection of the fetus's cells (rather than the

²⁰ See, e.g., Kypros H. Nicolaides, *Screening for Fetal Aneuploidies at 11 to 13 Weeks*, 31 *PRENATAL DIAGNOSIS* 7, 9–10 (2011). Serum screening is most often done in conjunction with fetal nuchal translucency (NT), a measure of the thickness of the fluid in the fetus's neck. Though serum screening can be performed as early as nine weeks, the optimal time for performing it in conjunction with NT is 12 weeks. *Id.* at 10.

²¹ Jaime Staples King, *Not This Child: Constitutional Questions in Regulating Noninvasive Prenatal Genetic Diagnosis and Selective Abortion*, 60 *UCLA L. REV.* 2, 10 (2012); Jennifer Czerwinski et al., *Maternal Serum Screening: Results Disclosure, Anxiety, & Risk Perception*, 27 *AM. J. PERINATOLOGY* 279, 281 (2010). Serum screening can indicate an elevated risk of a number of fetal genetic abnormalities, including cystic fibrosis, Down syndrome, and spina bifida.

²² *For Women and Their Families: A Guide to Understanding Prenatal Screening Tests for Down Syndrome, Trisomy 18, and Open Neural Tube Defects*, GENETICS EDUC. PROJECT 8 (Aug. 2007), https://www.mountsinai.on.ca/care/family-medicine-genetics-program/resources/prenatal_screening2008.pdf.

mother's) and accordingly carry a small risk of miscarriage.²³ Where the fetus survives, the majority of women undergoing these tests receive good news, as no genetic abnormality can be found. But for the small minority who receive a confirmed diagnosis of a genetic abnormality, CVS and amniocentesis mark the beginning of a challenging ethical and emotional journey.

Upon confirmation of a fetal abnormality, pregnant women must rely on medical professionals—doctors, midwives, nurses, and genetic counselors—to help them understand both the nature of their fetus's condition and how to respond. Unfortunately, existing research indicates that current efforts to educate and counsel pregnant women about prenatal genetic abnormalities consistently come up short in providing a complete picture. Be it Down syndrome, spina bifida, cystic fibrosis or any of the hundreds of other disorders current genetic screening and testing are able to detect, the vast majority of diagnosed prenatal genetic conditions are multivariate, can develop unpredictably, and are not fully understood, even by geneticists who have devoted their lives to studying them. Yet the time medical professionals spend discussing genetic analysis and potential diagnoses with pregnant women is astonishingly brief; one study found that during initial prenatal visits, doctors and midwives spent an average of 2.5 minutes discussing genetic counseling with women younger than 35 and 6.9 minutes discussing it with older women.²⁴

More troubling, the subsequent confirmation of a genetic abnormality tends to be presented as a binary—the relevant test is either positive or negative, with little explanatory nuance as to what exactly a positive result might mean with respect to the fetus's future quality of life.²⁵ Can a child with Down syndrome lead a happy life? Can children born with spina bifida overcome this disability and become happy, productive citizens? What is the range of outcomes for cystic fibrosis or sickle cell anemia? As will be shown in the following section, these questions tend

²³ See R. Akolekar et al., *Procedure-Related Risk of Miscarriage Following Amniocentesis and Chorionic Villus Sampling: A Systematic Review and Meta-Analysis*, 45 *ULTRASOUND OBSTETRICS GYNECOLOGY* 16, 16 (2015) (noting the oft-cited miscarriage rates of 1% for amniocentesis and 1%–2% for CVS, but arguing that the actual procedure-related risk is far lower).

²⁴ Barbara A. Bernhardt et al., *Prenatal Genetic Testing: Content of Discussions Between Obstetric Providers and Pregnant Women*, 91 *OBSTETRICS & GYNECOLOGY* 648, 648 (1998); cf. Philip Farrell & Norman Fost, *Prenatal Screening for Cystic Fibrosis: Where Are We Now?*, 141 *J. PEDIATRICS* 758, 760 (2002) (noting that educating an uninformed layperson to the point of making an informed decision about whether to undergo genetic screening for cystic fibrosis would take “an hour or more”).

²⁵ A number of genetic conditions can impact the fetus's quality of potential life in a wide array of ways, meaning that sometimes a given disorder will manifest itself through mild or hardly discernible symptoms. See, e.g., DUSTER, *supra* note 19, at 53 (highlighting children with sickle-cell anemia as an example of disparate outcomes—some live a full life with minor symptoms, while others experience excruciating pain and die at an early age).

to be left unaddressed, due to the selective presentation of information during the counseling process and the extraordinarily complicated nature of genetic diagnoses. Most often, rather than describing the range of potential quality-of-life outcomes genetically anomalous fetuses might experience, health care providers counsel patients with an emphasis on worst-case scenarios.

The result has been that a large majority of women receiving a diagnosis of a genetic abnormality abort their pregnancies,²⁶ frequently within days, and at times in as little as twenty-four hours.²⁷ The brevity of this timetable is notable because it is virtually impossible to digest the large corpus of unfamiliar, technical, scary, and potentially life-altering information inherent in a genetic diagnosis and make an informed choice in so short a period of time.²⁸ It follows that many of the choices being made are less than fully informed,²⁹ which is particularly problematic given the lasting impact of genetic terminations discussed in Part II.

Functioning properly, prenatal genetic counseling should serve as a conduit, taking expectant mothers from the petrifying wilderness of a genetic diagnosis to the informed choice that is right for them; this is the essence of the genetic counseling's nondirective aspiration. But as will be shown in the following section, genetic counseling is currently failing expectant mothers, leading to underinformed decisions to terminate that can produce long-standing, traumatic outcomes.

B. *Underinformed Choices and the Futility of Nondirectiveness*

Be it by licensed genetic counselors or otherwise,³⁰ prenatal genetic counseling plays a significant role in complicated pregnancies, helping

²⁶ “[F]our of five women who learn of a diagnostic test that produces positive indications of a genetic abnormality that will manifest symptoms choose abortion.” *Id.* at 70.

²⁷ See Korenromp et al., *supra* note 1, at 98 (finding that women who had terminated pregnancies on genetic grounds did so between one and ten days of diagnosis, with an average of 4.7 and a median of 4.4 days).

²⁸ See RAYNA RAPP, *TESTING WOMEN, TESTING THE FETUS: THE SOCIAL IMPACT OF AMNIOCENTESIS IN AMERICA* 113 (Routledge 1999) (noting that some women, despite telling genetic counselors that they understood what they have been told, report that they could not follow all the words and diagrams being used to explain genetics and the risk of disorders).

²⁹ See Farrell & Fost, *supra* note 24, at 761 (“In the best circumstances, there are still likely to be couples who will misunderstand and make reproductive decisions contrary to their own desires.”).

³⁰ Access to counselors who are members of the National Society of Genetic Counselors (NSGC) varies considerably, as they tend to be concentrated in certain large cities. See Kathryn Schleckser, Note, *Physician Participation in Direct-to-Consumer Genetic Testing: Pragmatism or Paternalism?*, 26 HARV. J.L. & TECH. 695, 725–26 (2013) (describing the high concentration of NSGC-member genetic counselors in urban areas such as New York, Philadelphia, and San Francisco and their relative dearth in and around cities such as New Orleans, Boise, and Fargo). Moreover, a recent search on the web page of the American Board of Genetic Counseling, the field's accrediting body, found that there are just twelve certified genetic counselors in Idaho (eleven of whom are in Boise), five in Mississippi, two in Wyo-

women determine which form of genetic analysis is right for them and interpret screening or testing results. Upon detection of a fetal anomaly, counselors help women decide whether to terminate the pregnancy,³¹ treat the fetus in utero, or manage the pregnancy and delivery with an eye toward raising a child with a potential disability.³² Unlike obstetricians and other health care professionals—who are often minimally trained and inadequately prepared to counsel patients in this manner (though they often do)³³—licensed genetic counselors are required to undergo two years of masters-level training designed to enable them to inform and counsel patients navigating their way through the numerous medical, ethical, and psychological issues at play in this realm.³⁴

In accordance with prevailing norms of nondirectiveness,³⁵ genetic counselors and others providing prenatal genetic counseling endeavor to avoid or downplay the social and political implications of the information they provide. Instead, genetic counselors emphasize their technical competence³⁶ in an effort to maintain the objective and scientific character of their communications. Genetic counselors generally provide patients with the data and risk considerations of the disorder, followed by open-ended questions (“How do you feel about those numbers?”) and active listening (“I hear you saying that you could/could not handle a child like that”).³⁷ In this regard, counselors play a dual role, acting as both information-giver and counselor.³⁸

Beyond these basic parameters, however, the manner in which genetic counseling plays out in practice varies considerably, as counseling must in each instance be tailored to a wide range of patient backgrounds and needs.³⁹ The combination of the counselor’s dual role and the cultural, religious, racial, intellectual, and economic diversity of the patient

ming, and one in West Virginia. See *Find a Counselor*, AM. BD. OF GENETIC COUNSELING, INC., https://abgcmember.goamp.com/net/ABGCwcm/Find_Counselor/ABGCwcm/Contact_Management/FindCounselor.aspx?hkey=94273207-1a6e-4c6d-ac24-0c6b3793c8cd (last visited, Aug. 4, 2015).

³¹ For a more complete historiography on the development of the genetic counselor, see RAPP, *supra* note 28, at 56–62.

³² Rachel Rebouché and Karen Rothenberg, *Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion*, 55 *How. L.J.* 983, 990 (2012); DUSTER, *supra* note 19, at 69 (“The counselor primarily provides information, elaborates options, answers complicated genetic questions, explains risk figures and probabilities, and offers a measure of emotional support and understanding. The counselor, according to ideology, does not hint, cajole or try to influence in a direction that is against the indications of the counselee.”).

³³ Rebouché & Rothenberg, *supra* note 32, at 990.

³⁴ RAPP, *supra* note 28, at 56–57.

³⁵ See *supra* note 5 and accompanying text.

³⁶ DUSTER, *supra* note 19, at 79.

³⁷ RAPP, *supra* note 28, at 59.

³⁸ DUSTER, *supra* note 19, at 83.

³⁹ *Id.* at 172 (“On the one hand, each counseling session is a unique configuration of personal experience, of familial and peer pressures . . . of religious and spiritual beliefs . . . of

population produces a matrix of possibilities that renders it impossible to develop a single, generally-applicable set of best practices for administering counseling in a manner that is truly nondirective.⁴⁰ A Catholic, young, wealthy white couple carrying a child with spina bifida, for example, is likely to enter a genetic counseling session with a different perspective and different concerns than an older, nonreligious, Latino couple of more limited means.

Given the diversity of the patient population and the inherent subjectivity of genetic counseling, it should come as no surprise that few parents experiencing prenatal genetic counseling find it to be neutral.⁴¹ Despite counselors' intent and their nondirective aspirations, "neutrality is virtually impossible" because "social values and priorities . . . are embedded in medical institutions and frameworks" and "insistence on impartiality can ultimately frustrate patients, some of whom want to receive expert advice from genetic practitioners."⁴² Not surprisingly, a genetic counselor's experience and background "will often determine whether the disorder will be explained to the patient in positive or negative terms."⁴³ There are even some counselors who "display surprise or distress upon hearing that a woman wants to bring to term a fetus identified as having a disability,"⁴⁴ regardless of a patient's beliefs and available resources. The result has been that despite—or perhaps because of—due consideration of the individual needs and background of each patient, "most clients seeking genetic counseling in conjunction with predictive testing will be given directive counseling,"⁴⁵ in large part because, as counselors themselves acknowledge, "staying in neutral is often a difficult task."⁴⁶

Though clear-cut advice is forbidden,⁴⁷ genetic counselors manage to counsel their patients directly in a number of ways. When asked "What do you think I should do?"—an inquiry occurring on average over

connections of specific histories to the genetic disease . . . and, of course, the social and cultural meanings attached to each [disorder].").

⁴⁰ DUSTER, *supra* note 19, at 82.

⁴¹ See, e.g., Barbara A. Bernhardt, *Empirical Evidence that Genetic Counseling Is Directive: Where Do We Go from Here?*, 60 AM. J. HUM. GENETICS 17, 19 (1997); Susan Michie et al., *Nondirectiveness in Genetic Counseling: An Empirical Study*, 60 AM. J. HUM. GENETICS 40 (1997).

⁴² ALEXANDRA M. STERN, *EUGENIC NATION: FAULTS AND FRONTIERS OF BETTER BREEDING IN MODERN AMERICA* 213 (Univ. of Cal. Press 2005).

⁴³ Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 862 (1999).

⁴⁴ Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING & DISABILITY RIGHTS* 33, (Erik Parens & Adrienne Asch eds., Georgetown Univ. Press 2000).

⁴⁵ Bernhardt, *supra* note 41, at 18.

⁴⁶ See RAPP, *supra* note 28, at 94.

⁴⁷ STERN, *supra* note 42, at 213.

five times during each counseling session⁴⁸—it becomes increasingly difficult over time for counselors to side-step the question and emphasize that it is the patient's personal decision.⁴⁹ Instead, counselors may “selectively reinforce” a patient's perceived inclination or general attitude,⁵⁰ “choose not to disclose certain information,” or “suggest what [he or] she considers the ‘most appropriate’ course of action for the patient under the circumstances.”⁵¹

This is not to fault genetic counselors, for the circumstances under which prenatal genetic counseling must take place render true nondirectiveness all but impossible. Given the sheer volume of information that could be conveyed to an expectant mother learning of a fetal abnormality and limited time, the counselor must be selective as to which information she presents. In determining which information to present, counselors must weigh what they perceive to be the potential personal impact (the ability of patients to cope with adversity given the relative strength of their support network), economic impact (the ability of patients to afford caring for a child with a genetic disorder), and social impact (the stigma that comes along with terminating pregnancy or caring for a child with a genetic disorder) in order to help them decide how to proceed.⁵²

Factoring in each of these concerns manifests itself in the form of deciding not only “*what* information is included in a consultation,” but also how to frame the facts presented.⁵³ Indeed, it is now clear that “cultural, socioeconomic, educational, and ethical factors significantly affect the way counselors describe genetic disorders *and their possible outcomes*.”⁵⁴ One result of this selective approach has been that the choices of individuals are in some instances all but “preconstructed by the categories of disease” affecting the fetus.⁵⁵ Such preconstruction is diametrically opposed to the nondirectiveness that should characterize prenatal genetic counseling.

⁴⁸ Bernhardt, *supra* note 41, at 17.

⁴⁹ See RAPP, *supra* note 28, at 96–100.

⁵⁰ Bernhardt, *supra* note 41, at 17.

⁵¹ Alan J. Belsky, *Injury As A Matter of Law: Is This the Answer to the Wrongful Life Dilemma?*, 22 U. BALT. L. REV. 185, 268 n.196 (1993) (“The counselor may well justify nondisclosure of certain diagnoses on the assumption that the parents, upon receipt of such information, may decide ‘unreasonably’ to abort the fetus.”).

⁵² DUSTER, *supra* note 19, at 82–83.

⁵³ Bernhardt, *supra* note 41, at 18 (“Genetic counselors always have the power to influence clients by choosing to discuss one aspect of a situation while ignoring or downplaying another.”).

⁵⁴ Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 862 (1999) (emphasis added).

⁵⁵ See Evelyn Fox Kelly, *Nature, Nurture, and the Human Genome Project*, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 296 (Daniel J. Kevles & Leroy Hood eds., Harvard Univ. Press 1992).

The challenges of prenatal genetic counseling do not end there. Regardless of which information counselors choose to present, there remains a no less important concern that expectant mothers often fail to grasp the limited information they do receive due to its complexity. This is a particular concern for less educated pregnant women because counselors tend to “communicate very similar content across cases, as if [the] variability and uniqueness [of each session] were momentarily suspended or ‘bracketed.’”⁵⁶ Some patients, despite politely feigning understanding during the counseling session, later report that they could not follow all the words and diagrams being used to explain genetics and the risk of disorders.⁵⁷ In one study, as many as 30% of counselees could not recall crucial risk figures that counselors presented during consultation,⁵⁸ which suggests that nearly a third of these patients made a less than fully informed reproductive choice.

This comprehension gap arises out of both the inadequacy of the literature and communication provided and the patients’ tendency to blame themselves for not understanding the complicated information presented to them.⁵⁹ The content of the counseling session is by its nature overwhelming, and it tends to be conveyed in a manner that is antithetical to comprehension, “muted by the professionalism of the bureaucratic style of communication.”⁶⁰ But regardless of its source, the gap between what counselors say and what patients hear is now well established and, given the stakes, should be cause for great concern.

It should now be clear that the selective presentation of information based on counselors’ preconceptions of the disorder at issue and patient characteristics—coupled with the failure of many counselees to understand the information presented to them—has made it so that women frequently make underinformed choices regarding genetic abortions. And given the widely recognized near impossibility of nondirectiveness described above, it should be equally clear that prenatal genetic counseling is often directive⁶¹—albeit to varying degrees—and at times can act to encourage the termination of genetically anomalous fetuses. To be sure, some women make the choice that is right for them despite being underinformed and receiving directive counseling. But others do not. The following Part focuses on the experience of those who choose to terminate on genetic grounds, highlighting the unique and troubling psychological

⁵⁶ DUSTER, *supra* note 19, at 172.

⁵⁷ See Rapp, *supra* note 28, at 113.

⁵⁸ PETER D. TURNPENNY & SIAN ELLARD, *EMERY’S ELEMENTS OF MEDICAL GENETICS* 268 (14th ed. 2011).

⁵⁹ See RAPP, *supra* note 28, at 113.

⁶⁰ DUSTER, *supra* note 19, at 173.

⁶¹ TURNPENNY & ELLARD, *supra* note 58, at 268 (noting that of couples attending genetic counseling, “approximately 50% have been influenced to some extent”).

impacts these abortions have on the women who have them and their families. This trauma is perhaps the greatest cost of prenatal genetic counseling in its current form and serves as the basis for the reforms set forth in Part V of this Article.

II. THE UNIQUE IMPACT OF GENETIC TERMINATIONS

It bears repeating that a pregnant woman learning of a prenatal genetic abnormality usually opts to abort the pregnancy,⁶² and does so within an average of under five days.⁶³ Usually occurring during the second trimester, a genetic termination is distinct from the vast majority of traditional abortions both in timing and, more importantly, “in that it is an initially wanted pregnancy.”⁶⁴ Put differently, pregnant women considering genetic abortions have already declined to terminate and have begun preparing to bring a child into the world. The jarring discovery of a fetal abnormality forces these women into an unwelcome and uncomfortable revisitation of the abortion question, and, as will be shown below, when women choose to abort on genetic grounds, it is “much more difficult to handle emotionally, psychologically, and physiologically.”⁶⁵ In this regard, it is the nature of the termination rather than its timing that is most significant—even where the abortion takes place relatively early, feelings of guilt, failure, genetic inferiority, revulsion, fear, grief, helplessness, depression, and doubt about the correctness of the decision can engulf women who terminate on genetic grounds.⁶⁶

Stillbirth is perhaps a better analogue to genetic terminations: in both cases there is a wanted pregnancy ending in fetal demise and resulting in a profound sense of loss that tends to resonate to a greater degree than the termination of an unwanted pregnancy. But genetic terminations are unlike stillbirth in that the mother (rather than incompatibility with life) decides the ultimate fate of the fetus.⁶⁷ This distinction is significant because women choosing to terminate on genetic grounds possess an agency that can be informed by prenatal genetic counseling so as to mitigate and perhaps overcome the profound loss many of them experience. For them, unlike those stricken with a stillborn child, there is hope.

⁶² See DUSTER, *supra* note 19, at 70 (“[F]our of five women who learn of a diagnostic test that produces positive indications of a genetic abnormality that will manifest symptoms choose abortion.”).

⁶³ See Korenromp et al., *supra* note 1, at 98–99.

⁶⁴ *Id.* at 95.

⁶⁵ See DUSTER, *supra* note 19, at 179.

⁶⁶ See Korenromp et al., *supra* note 1, at 100–02; see also *id.* at 104 (“Even if the pregnancy is terminated at an early stage, the parents have to cope with the loss of a child and the loss of an envisaged future.”).

⁶⁷ See *id.* at 95.

The unique trauma experienced by women who terminate on genetic grounds is well documented in the literature. Termination of pregnancy due to a fetal anomaly has been described as a “major life event” for almost all women⁶⁸ and a “traumatic life event with high psychological impact,”⁶⁹ “commensurate with those experienced over the loss of a spouse, a parent, or a child.”⁷⁰ After termination, it is not uncommon for women to second-guess their choice, and in one study “nearly all the women . . . report[ed] feelings of wanting to die” in the weeks following the procedure.⁷¹

There are three reasons why the psychological impact of these terminations is so severe. First, there is the sense of agency referenced above. Unlike a stillbirth or other perinatal loss, it is the mother who decides to end the life of her initially wanted fetus. As one study explains, “genetic abortions are especially poignant because the parents take an active part in the baby’s death.”⁷²

Second, women who terminate on genetic grounds experience a severe sense of isolation, finding it difficult to discuss their experience with even their closest friends and loved ones. The poles of the abortion debate help to frame this isolation: “The pro-choice group cannot accept the love the woman feels for the entity she calls her ‘baby’; the pro-life group cannot condone the woman’s willingness to terminate the pregnancy.”⁷³ Because a genetic termination does not fit within the traditional abortion narrative, women find themselves with “little support and

⁶⁸ See, e.g., Marijke J. Korenromp et al., *Long-term Psychological Consequences of Pregnancy Termination for Fetal Abnormality: A Cross-sectional Study*, 25 *PRENATAL DIAGNOSIS* 253 (2005); Anette Kersting et al., *Psychological Impact on Women After Second and Third Trimester Termination of Pregnancy Due to Fetal Anomalies Versus Women After Preterm Birth—A 14-month Follow up Study*, 12 *ARCHIVES WOMEN’S MENTAL HEALTH* 193, 200 (2009).

⁶⁹ Anette Kersting & Birgit Wagner, *Complicated Grief After Perinatal Loss*, 14 *DIALOGUES CLINICAL NEUROSCIENCE* 190 (2012); see also K.A. Salvesen et al., *Comparison of Long-term Psychological Responses of Women After Pregnancy Termination Due to Fetal Abnormalities and After Perinatal Loss*, 9 *ULTRASOUND OBSTETRICS GYNECOLOGY* 83–84 (1997) (noting that by one measure the acute psychological response to a termination due to fetal anomaly is comparable to the response to a diagnosis of breast cancer or being raped).

⁷⁰ ELIZABETH RING-CASSIDY & IAN GENTLES, *WOMEN’S HEALTH AFTER ABORTION: THE MEDICAL AND PSYCHOLOGICAL IMPACT* 161 (2002) (quoting Mary Sellar et al., *Grief and Mid-Trimester Fetal Loss*, 13 *PRENATAL DIAGNOSIS* 341, 346 (1993)).

⁷¹ Judith L.M. McCoyd, *Pregnancy Interrupted: Loss a Desired Pregnancy After Diagnosis of Fetal Anomaly*, 28 *J PSYCHOSOMATIC OBSTETRICS & GYNECOLOGY* 37, 45 (2007).

⁷² RING-CASSIDY & GENTLES, *supra* note 70, at 160–61 (quoting Aliza Kolker & B. Meredith Burke, *Grieving the Wanted Child: Ramifications of Abortion After Prenatal Diagnosis of Abnormality*, 14 *HEALTH CARE FOR WOMEN INT’L* 513, 524 (1993); see also *id.* at 161 (quoting Bruce D. Blumberg et al., *The Psychological Sequelae of Abortion Performed for a Genetic Indication*, 122 *AM. J. OBSTETRICS & GYNECOLOGY* 799, 805 (1975)) (highlighting “the role of decision making and the responsibility associated with selective abortion” as factors perhaps explaining “the more serious depression” after genetic terminations).

⁷³ McCoyd, *supra* note 71, at 43.

no advocacy group to embrace the sort of ‘choice’ they must make.”⁷⁴ All too often they experience this unique suffering alone. One result of this isolation is that some women who do seek support simply lie, telling those around them that they lost their fetus to a miscarriage rather than a genetic abortion.⁷⁵

Third, and related to the first two, there is an overriding sense of guilt and shame that accompanies genetic terminations. This can take two forms. On one hand, “there is a sense of failure elicited by the fact of the fetal anomaly. Parents may feel that they are to blame for their child’s imperfection.”⁷⁶ On the other hand is the “guilt generated by having made the decision to terminate the pregnancy.”⁷⁷

The combined impact of these three factors—agency, isolation, and guilt—has been a persistent finding of notably high rates of grief, depression, and post-traumatic stress in women who terminate their pregnancies because of a fetal abnormality. The grief women experience is extraordinary, rising for some to the level of clinical diagnoses of “complicated grief”⁷⁸ or persisting to the point of becoming “pathological.”⁷⁹ Grief rising to this level is characteristically “intense,” lasts “longer than would be expected according to social norms,” and “causes impairment in daily functioning.”⁸⁰ It is also associated with “sleep disturbance, substance

⁷⁴ *Id.*

⁷⁵ See, e.g., Emma F. France et al., *What Parents Say About Disclosing the End of Their Pregnancy Due to Fetal Abnormality*, 29 MIDWIFERY 24, 30 (2013) (“Most parents were selective in who they told they had terminated the pregnancy because of a fetal abnormality, telling less close friends and acquaintances that they had had a miscarriage or that the baby had died.”); Kersting & Wagner, *supra* note 69, at 190 (“As some people may experience condemnation by sections of society that do not approve of the decision to terminate, a number of families decide to pretend that the loss was due to a miscarriage.”) (quoting Euna M. August et al., *Infant Mortality and Subsequent Risk of Stillbirth: A Retrospective Cohort Study*, 118 BJOG 1636 (2011)); RING-CASSIDY & GENTLES, *supra* note 70, at 162 (noting that “many women are reluctant to admit that they have had a genetic abortion and will tell relatives and friends they have had a miscarriage instead”) (citing Seller et al., *supra* note 70, at 343).

⁷⁶ RING-CASSIDY & GENTLES, *supra* note 70, at 162 (citing one study finding that 61% of women and 32% of men felt this way and another finding that 43% of women do).

⁷⁷ *Id.* (citing a study finding that 40% of women and 9% of men feel this way).

⁷⁸ Kersting & Wagner, *supra* note 69, at 190 (noting that complicated grief has “been documented in parents years after a termination on the grounds of abnormality”). Complicated grief is “unusually severe and prolonged, and it impairs function in important domains.” M. Katherine Shear, *Complicated Grief*, 372 NEW ENG. J. MED. 153, 154 (2015). Its characteristic symptoms include “intense yearning, longing, or emotional pain, frequently preoccupying thoughts and memories of the deceased person, a feeling of disbelief or an inability to accept the loss, and difficulty imagining a meaningful future without the deceased person.” *Id.*

⁷⁹ Kersting & Wagner, *supra* note 69, at 191 (“Pathological grief was found to be particularly high in women after termination of an abnormal pregnancy.”). *But see* Kathleen Keefe-Cooperman, *A Comparison of Grief as Related to Miscarriage and Termination for Fetal Abnormality*, 50 OMEGA: J. DEATH & DYING 281, 297 (2005) (finding that women who terminate due to a fetal abnormality do not manifest worse grief symptoms than those who experience a miscarriage).

⁸⁰ Shear, *supra* note 78, at 154.

abuse, suicidal thinking and behavior, and abnormalities in immune functions.”⁸¹ These grief symptoms can be compounded in women who have had genetic abortions, some of whom feel they are not entitled to the grief they are experiencing because it is a direct result of their decision.⁸²

Women who terminate due to a fetal abnormality also experience high levels of depression,⁸³ which generally entails “the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect [their] capacity to function.”⁸⁴ This depression can be short-lived, or can persist for many years after termination.⁸⁵ But regardless of duration, the depression women experience after genetic terminations has been noted across the literature⁸⁶ and remains a common risk factor.

Lastly, the most significant outcome for these women found in the literature is a high rate of post-traumatic stress. Post-traumatic stress is a familiar outcome for combat veterans and victims of rape or sexual assault, torture, terrorist attack, or natural disaster.⁸⁷ The symptoms of post-traumatic stress vary, but can include recurrent, intrusive memories of the traumatic event, flashbacks in which the individual relives the event, and adverse psychological and physiological reactions upon exposure to cues that resemble or symbolize the event.⁸⁸

Mothers often experience the death of a fetus by way of a termination for a fetal abnormality more of a trauma than a loss.⁸⁹ The resultant post-traumatic stress occurs at an alarmingly high rate. One study found

⁸¹ *Id.*

⁸² See McCoyd, *supra* note 71, at 45 (citing KENNETH J. DOKA, *DISENFRANCHISED GRIEF: RECOGNIZING HIDDEN SORROW* 368 (1989)).

⁸³ RING-CASSIDY & GENTLES, *supra* note 70, at 162 (observing that “following a genetic abortion,” depression is “very common”) (citing P. Donnai et al., *Attitudes of Patients After “Genetic” Termination of Pregnancy*, 282 *BRITISH MED. J.* 621, 622 (1981); Blumberg et al., *supra* note 72, at 805); see also *id.* (speculating that, factoring in the likely high rate of denial in self reporting, the incidence of depression following a selective abortion may be as high as 92% for women and 82% for men) (citing Blumberg et al., *supra* note 72, at 805).

⁸⁴ AMERICAN PSYCHIATRIC ASSOCIATION, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS* 155 (5th ed. 2013) [hereinafter *DSM-V*].

⁸⁵ See Marijke J. Korenromp et al., *Psychological Consequences of Termination of Pregnancy for Fetal Anomaly: Similarities and Differences Between Partners*, 25 *PRENATAL DIAGNOSIS* 1226, 1231 (2005).

⁸⁶ See, e.g., Marijke J. Korenromp et al., *Adjustment to Termination of Pregnancy for Fetal Anomaly: A Longitudinal Study in Women at 4, 8, and 16 Months*, 201 *AM. J. OBSTETRICS & GYNECOLOGY* 160.e1, 160.e3 (2009) (finding rates of depression of 27.9%, 19.7%, and 13.1% at 4, 8, and 16 months after termination, respectively); Kersting et al., *supra* note 68, at 199 (finding that women who terminate due to fetal anomalies in the second or third trimester score high for depressive symptoms fourteen months after termination).

⁸⁷ *DSM-V*, *supra* note 84, at 274.

⁸⁸ *Id.* at 271.

⁸⁹ See Korenromp et al., *supra* note 68, at 259 (observing that “in the long term, women apparently experience [termination of pregnancy for fetal abnormality] more as a trauma than

that post-traumatic stress was exhibited by 45% of women 14 days after termination, 35.3% six months after termination, and nearly one in three (30.9%) fourteen months after termination.⁹⁰ These numbers far exceed the respective figures for women experiencing pre-term birth (25.8%, 22%, and 21%) and women who had delivered a healthy child (7.7%, 3.9%, and 4.3%).⁹¹ Another study at four months after termination found the rate of post-traumatic stress symptoms for women who had terminated for fetal anomalies to be 44%, ten times higher than after a normal delivery.⁹²

These post-termination outcomes are not limited to expecting mothers; fathers and living children experience psychological impacts from genetic terminations as well. Though generally manifesting symptoms at a lower rate than their partners, men also suffer from grief,⁹³ depression,⁹⁴ and post-traumatic stress⁹⁵ after genetic terminations. Moreover, some men find it “harder to access emotional support” than their partners “because of expectations about how men ‘should’ deal with emotions and the stigma of public displays of distress by men,” which in turn begets a greater sense of isolation that can have a negative impact on their emotional health.⁹⁶ Men also report “that nobody asked them how they felt or how they were coping” after termination,⁹⁷ and because they often focus their attention on supporting their partners (and families), men tend to suppress their feelings throughout this traumatic experience.⁹⁸

as a loss”); Korenromp et al., *supra* note 85, at 1231 (finding that both women and men experienced fetal terminations “more as a trauma than as a loss event”).

⁹⁰ Kersting et al., *supra* note 68, at 198.

⁹¹ *Id.*

⁹² Marijke J. Korenromp et al., *A Prospective Study on Parental Coping 4 Months After Termination of Pregnancy for Fetal Anomalies*, 27 *PRENATAL DIAGNOSIS* 709, 712 (2007).

⁹³ *See id.* (finding symptoms of grief in 2.4% of men—compared to 9.7% of women—four months after termination).

⁹⁴ *See id.* (finding symptoms of depression in 15.8% of men—compared to 28.2% of women—four months after termination).

⁹⁵ *See id.* (finding symptoms of post-traumatic stress in 21.6% of men—compared to 44% of women—four months after termination).

⁹⁶ France et al., *supra* note 75, at 31; *see also* Fiona M. Robson, “Yes!—A Chance to Tell My Side of the Story”: A Case Study of a Male Partner of a Woman Undergoing Termination for a Fetal Abnormality, 7 *J. HEALTH PSYCHOL.* 183, 190 (2002) (“The resulting lack of social support can complicate the grieving process and can become more intensified because of the expectation of stoicism in the male gender, in addition to the social expectations that men should not grieve openly.”).

⁹⁷ Robson, *supra* note 96, at 190 (citing F.A. Murphy, *The Experience of Early Miscarriage from a Male Perspective*, 7 *J. CLINICAL NURSING* 325 (1998); M. White-Van Mourik, *The Psychological Sequelae of a Second-Trimester Termination of Pregnancy for Fetal Abnormality*, 12 *PRENATAL DIAGNOSIS* 189 (1992)).

⁹⁸ *See* Robson, *supra* note 96, at 191.

Finally, children learning of the death of what was to become their little brother or sister also suffer. Because they have trouble separating “the concept of ‘fetus’ from the concept of ‘baby,’” young children, unable to comprehend the complexity of their parents’ decision, mourn the loss as they would mourn the loss of a living baby.⁹⁹ Psychological impacts on children have been noted whether parents provide a partial (omitting discussion of the parents’ choice) or complete explanation of the circumstances of the fetal demise.¹⁰⁰ Even where parents provide no explanation of the loss to their very young children, there can be behavioral changes, such as motor regression.¹⁰¹ And regardless of what they are told, some children experience adverse effects of their parents’ anxiety and distress as they cope with the termination.¹⁰²

As this section has shown, women who terminate their pregnancies because of a fetal abnormality experience elevated rates of significant psychological outcomes, namely grief, depression, and post-traumatic stress. In this regard, these abortions are unlike abortions of unwanted pregnancies (the vast majority), which have relatively minor psychological impacts.¹⁰³ Though similar to stillbirth because in both cases a wanted child does not come into being, genetic terminations are distinct in that the parents must assent to the fetus’s demise, which results in a greater sense of isolation and guilt. And although would-be mothers bear the brunt of the psychological impact after termination, their partners and children are not exempt.

These severe psychological outcomes underscore the significance of the decision whether to terminate for a fetal abnormality. Despite its best intentions—and often for good reason—prenatal genetic counseling does not adequately prepare women for the magnitude and consequences of the decision that they must make. Picking up on this observation, Congress and several states have passed legislation in recent years aimed at providing better information for women in this predicament. The following Part discusses these legislative responses and explains why they do not go far enough.

⁹⁹ RING-CASSIDY & GENTLES, *supra* note 70, at 164.

¹⁰⁰ In one study, children receiving a partial explanation “expressed sadness, disappointment, and guilt.” *Id.* Older children receiving a complete explanation had “marked and disturbing reactions.” *Id.*

¹⁰¹ *Id.*

¹⁰² See France et al., *supra* note 75, at 31; RING-CASSIDY & GENTLES, *supra* note 70, at 164.

¹⁰³ See *supra* note 10 and accompanying text.

III. FEDERAL AND STATE RESPONSES

A. *Federal Response: the PPDCAA*

In recognition of the continued growth of prenatal genetic analysis and the inadequacies of the information and support women carrying genetically anomalous fetuses receive, Congress passed the Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCAA) in 2008. Signed into law by President Bush in October of that year, the Act has three stated purposes:

- (1) increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to *provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes*;
- (2) *strengthen existing networks of support* through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and provider outreach programs; and
- (3) ensure that patients *receive up-to-date, evidence-based information about the accuracy of the test*.¹⁰⁴

In order to accomplish these goals—the common theme of which is to provide prospective parents with accurate information in order to allow them to make informed decisions about raising children with genetic disorders¹⁰⁵—the Act empowers the Secretary of the Department of Health and Human Services to authorize and oversee certain activities by the heads of the National Institutes of Health, Centers for Disease Control and Prevention, or Health Resources and Services Administration.¹⁰⁶ Included among these activities are the collection and dissemination of current, evidence-based information about genetic disorders and the coordination of access to supportive services for families of patients with genetic diagnoses.¹⁰⁷

¹⁰⁴ Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110–374, § 2(1)–(3), 122 Stat. 4051, 4051 (2008) (emphasis added).

¹⁰⁵ See Rebouché & Rothenberg, *supra* note 32, at 993 (2013) (citing John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469, 477 (2011)).

¹⁰⁶ 42 U.S.C. § 280g-8(b)(1) (2012).

¹⁰⁷ 42 U.S.C. § 280g-8(b)(1)(A)–(B) (2012). The suggested means of doing so under the PPDCAA include telephone hotlines, improved outreach and peer-to-peer counseling programs, the creation of national or local registries of families willing to adopt children with genetic disorders, and the establishment of education services for medical professionals who

The PPDCAA's goal of providing accurate, up-to-date, and balanced information to prospective and current parents of children with genetic disorders drew bipartisan support. Raised in the Senate by Senators Brownback and Kennedy—as strange bedfellows as one could imagine—the PPDCAA worked its way through both houses of Congress the same week¹⁰⁸ and was signed into law just two weeks later.¹⁰⁹ But the Act did not emerge from the legislative process unscathed. Whereas an earlier version included a request for \$5 million of funding to support its objectives,¹¹⁰ the PPDCAA as passed contained no funding provision. To date, it has been funded at only a fraction of the requested amount,¹¹¹ and it has had minimal impact in providing families with the essential information of its aim. Though Congress should be applauded for acknowledging the importance of filling the significant gaps in the information women carrying genetically anomalous fetuses currently receive, the underfunding of the PPDCAA represents a missed opportunity to address this important need.¹¹²

B. State Responses

In addition to the federal effort embodied in the PPDCAA, eleven states have enacted measures aimed at providing the most current, evidence-based information regarding prenatally (and postnatally) diagnosed genetic conditions, such as Down syndrome, and offering various

provide, interpret, or inform parents of the results of prenatal genetic diagnostics. *Id.* § 280g-8(b)(1)(B)(i)–(v).

¹⁰⁸ See 154 CONG. REC. S9341 (Sept. 23, 2008) (showing that the bill passed in the Senate by unanimous consent on September 23, 2008); 154 CONG. REC. H9920 (Sept. 25, 2008) (showing that it passed in the House on September 25, 2008 under a suspension of the rules, a procedure for bills having at least a 2/3 majority of support).

¹⁰⁹ 122 Stat. 4051 (2008) (showing that the Act was signed into the law on October 8, 2008).

¹¹⁰ See Prenatally and Postnatally Diagnosed Conditions Awareness Act, S. 1810, 110th Cong. (as introduced July 18, 2007).

¹¹¹ See *Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 2012: Hearings Before a Subcomm. of the Comm. of Appropriations, Part 2B*, 112th Cong. 1128 (2011) (showing that measures relating to the PPDCAA have received funding of \$1,000,000 in FY 2009, \$499,000 in FY 2010, and \$500,000 in FY 2011); HEALTH RES. & SERVS. ADMIN., DEP'T OF HEALTH & HUMAN SERVS., FY 2012 JUSTIFICATION OF ESTIMATES FOR APPROPRIATIONS COMMITTEES 235, <http://www.hrsa.gov/about/budget/budgetjustification2012.pdf> (showing DHHS's ultimately unfunded request for \$499,000 in FY 2012); HEALTH RES. & SERVS. ADMIN., DEP'T OF HEALTH & HUMAN SERVS., FY 2013 JUSTIFICATION OF ESTIMATES FOR APPROPRIATIONS COMMITTEES 35–38, 382, <http://www.hrsa.gov/about/budget/budgetjustification2013.pdf> (listing “congenital disabilities” under the PPDCAA as an “unfunded authorization” for FY 2013 and noting that the “program was discontinued in fiscal year 2011”).

¹¹² For a more detailed discussion of the PPDCAA's shortcomings and areas of potential improvement, see Part V.A.

support services.¹¹³ The diversity of states passing such legislation—which include liberal strongholds Massachusetts and Maryland, traditional swing states Pennsylvania, Ohio, Florida, and Virginia, and deeply conservative Kentucky, Kansas, and Louisiana—indicates that fostering greater understanding of prenatally diagnosed conditions, and providing adequate support, is an issue of bipartisan concern.¹¹⁴ That nine of the eleven states have passed pro-information legislation since 2012,¹¹⁵ and in response to the PPDCAA's shortcomings,¹¹⁶ indicates that fostering improved distribution of information to women considering their reproductive choices after learning of a fetal anomaly is an emergent topic drawing increasing legislative attention in the states.

A recent piece of state legislation, Ohio's Down Syndrome Information Act (DSIA), provides an illustrative example. Enacted in December

¹¹³ See OHIO REV. CODE ANN. § 3701.69 (2014); 35 PA. CONS. STAT. ANN. § 6244 (2014); FLA. STAT. § 383.141 (2012); MASS. GEN. LAWS ANN. ch. 111, § 70H (2012); DEL. CODE ANN. tit. 16, § 801B (2014); MD. CODE ANN., HEALTH-GEN. § 20-1502 (2014); LA. STAT. ANN. § 40:1300.392 (2014); KY. REV. STAT. ANN. § 211.192 (2013); KAN. STAT. ANN. § 65-1,259 (2013); MO. ANN. STAT. § 191.923 (2007); VA. CODE ANN. § 54.1-2403.01 (2008). Two other states, New Jersey and Oklahoma, also have similar pending legislation. In Oklahoma, the bill was introduced in February 2013, but there has not been any activity since it was referred to committee. See S.B. 586, 54th Leg., 1st Sess. (Okla. 2013). In New Jersey, a bill was introduced on May 22, 2014, and there has not been any update on the bill since that time. See Assem. B. 3233, 216th Leg., 1st Sess. (N.J. 2014).

¹¹⁴ To take the two most recent examples, Pennsylvania passed the Down Syndrome Prenatal and Postnatal Education Act by a vote of 50-0 in the Senate and a 196-4 vote in the House. See *House Roll Calls; House of Representatives Session of 2013–2014 Regular Session*; PA. HOUSE OF REPS., http://www.legis.state.pa.us/CFDOCS/Legis/RC/Public/rc_view_action2.cfm?sess_yr=2013&sess_ind=0&rc_body=H&rc_nbr=1592 (last visited Feb. 21, 2016); *Senate Roll Calls, Senate of Pennsylvania Session of 2013–2014 Regular Session*, PA. STATE SENATE, http://www.legis.state.pa.us/CFDOCS/Legis/RC/Public/rc_view_action2.cfm?sess_yr=2013&sess_ind=0&rc_body=S&rc_nbr=660 (last visited Feb. 21, 2016). And, Ohio's Down Syndrome Information Act passed with no opposing votes. See *Unofficial Votes for House Bill 552*, OHIO GEN. ASSEMB. ARCHIVES, http://archives.legislature.state.oh.us/votes.cfm?ID=130_HB_552 (last visited Feb. 21, 2016).

¹¹⁵ Massachusetts led the way in 2012, followed by Florida (2012), Kansas and Kentucky (2013), and Louisiana, Delaware, Maryland, Pennsylvania, and Ohio (2014). The other two states, Virginia and Missouri, passed their legislation in 2007.

¹¹⁶ Christine Williams, *State Law Provides Information, Support After Down Syndrome Diagnosis: Massachusetts Legislation Could Be Model for Giving Help to Parents of Children with Down Syndrome*, OUR SUNDAY VISITOR (Oct. 17, 2012), <https://www.osv.com/OSVNewswweekly/ByIssue/Article/TabId/735/ArtMID/13636/ArticleID/9031/State-law-provides-information-support-after-Down-syndrome-diagnosis.aspx#sthash.wT76GhPt.dpuf> (outlining that the original intent behind the Massachusetts law, which propelled the state law movement, was to “augment the federal legislation”); *Questioning Objections to Chloe's Law*, JEROME LEJEUNE FOUND. (June 29, 2014), <http://lejeuneusa.org/node/608#.VKtVWivF-Sr> (“The need for Chloe's law is two-fold: [1] the Kennedy-Brownback Act has never been funded or implemented, which is why states have taken on state-level measures; and [2] while professional guidelines recommend offering prenatal testing for Down syndrome to all patients, those same guidelines recommend that patients receive up-to-date, accurate information about Down syndrome and referral to parent support organizations, but that is not happening with the same regularity as the offering of prenatal testing.”).

of 2014, the DSIA empowers Ohio's department of health to create a current, evidence-based Down syndrome information sheet that includes: a description of the syndrome, "including its causes, effects on development, and potential complications"; diagnostic tests available; treatment and therapy options; and contact information for organizations that provide Down syndrome support and educational services at the national, state, and local level.¹¹⁷ The DSIA further provides that the information sheet shall be made available on the department of health's website, and that copies of it shall be distributed to any patient under the care of state-licensed health care professionals or facilities who receives a test result indicating, or a diagnosis of, Down syndrome.¹¹⁸

Six states—Pennsylvania, Maryland, Delaware, Louisiana, Kentucky, and Massachusetts—take an approach similar to Ohio's in that they address their legislation specifically to Down syndrome and focus on the collection and distribution of certain information about the condition and support services available.¹¹⁹ There are, however, some notable distinctions. Kentucky's statute, for example, addresses itself to both Down syndrome and spina bifida.¹²⁰ Maryland, though requiring that its health department gather relevant information and distribute it to all applicable health care providers and facilities, crucially leaves to the department's discretion whether to provide that information to expectant parents receiving a Down syndrome diagnosis.¹²¹ And Louisiana, reflecting its conservative political climate, explicitly bars any mention of abortion as a "neutral or acceptable option" in the Down syndrome materials it requires expectant mothers to receive.¹²² Despite these distinctions, each of these seven states has taken the same general approach aimed at providing more accurate and balanced information to women considering terminating their pregnancies because of Down syndrome.

Four states—Kansas, Missouri, Virginia, and Florida—have taken a broader approach, addressing their legislation more generally to conditions diagnosed prenatally, postnatally, or both. In this regard, they are

¹¹⁷ OHIO REV. CODE ANN. § 3701.69(A)(1)–(2) (2014).

¹¹⁸ *Id.* § 3701.69(B) (2014). The health care professionals covered are physicians, nurse-midwives, genetic counselors, hospitals, maternity units, newborn care nurseries, maternity homes, and birthing centers. *Id.*

¹¹⁹ See 35 PA. CONS. STAT. ANN. § 6244 (2014); MD. CODE ANN., HEALTH-GEN. § 20-1502 (2014); DEL. CODE ANN. tit. 16, § 801B (2014); LA. REV. STAT. ANN. § 40:1300.392 (2014); KY. REV. STAT. ANN. § 211.192 (2013); MASS. GEN. LAWS ANN. tit. 111 § 70H (2012).

¹²⁰ See KY. REV. STAT. ANN. § 211.192 (2013).

¹²¹ MD. CODE ANN., HEALTH-GEN. § 20-1502(C)(1) (2014) ("On receipt of a positive test result from a test for Down syndrome, a health care facility or health care provider *may* provide to the expectant parent who receives a prenatal test result for Down syndrome or the parent of the child diagnosed with Down syndrome the written information provided or made available by the Department under subsection (b) of this section.") (emphasis added).

¹²² LA. REV. STAT. ANN. § 40:1300.392(A)(3) (2014).

more closely aligned with the federal PPDCAA than the Down-syndrome-specific legislation in the seven states described above. Kansas's legislation is potentially the most robust and contains elements that can serve as a model for other states. It speaks specifically to the collection and dissemination of "evidence-based information" about "Down syndrome and other prenatally or postnatally diagnosed conditions" and the provision of "new or existing supportive services," including outreach programs to provide expecting parents with the "range of outcomes for individuals living with the diagnosed condition," the development of "local peer support programs to effectively serve women" who receive a diagnosis, and the establishment of a "network of local registries of families willing to adopt newborns with Down syndrome or other prenatally or postnatally diagnosed conditions."¹²³ Unfortunately, none of these steps are required under Kansas's legislation; their creation and implementation are at the discretion of the Secretary of the Department of Health and Environment.¹²⁴

The three other states that have not taken a Down-centric approach have statutes that reflect similar concerns, but are less specific than Kansas's. Missouri's legislation, relating only to prenatally diagnosed conditions, requires that health care professionals provide parents with relevant medical and testing information as well as information regarding "resources for obtaining support services for such conditions," including "support programs for parents and families."¹²⁵ Florida imposes similar requirements.¹²⁶ Virginia's legislation, though broad in scope—covering "any fetal health condition identified by prenatal genetic testing or prenatal screening procedures"—requires only that medical information be provided to the parents.¹²⁷ Referrals to "support service providers," including "education and support programs," are discretionary.¹²⁸

Taken as a whole, these eleven state statutes address similar concerns pertaining to the inadequacy of information pregnant women receive upon learning of a fetal abnormality and considering terminating their pregnancies.¹²⁹ That overall more than one in five states have

¹²³ See KAN. STAT. ANN. § 65-1,259(a) (2013).

¹²⁴ *Id.*

¹²⁵ MO. REV. STAT. § 191.923(3) (2007).

¹²⁶ See FLA. STAT. § 383.141(2) (2012).

¹²⁷ VA. CODE ANN. § 54.1-2403.01(B) (2008).

¹²⁸ *Id.*

¹²⁹ See, e.g., Memorandum from Jim Marshall, Representative, to members of the Pennsylvania House of Representatives (Mar. 11, 2014), <http://www.legis.state.pa.us/cfdocs/Legis/CSM/showMemoPublic.cfm?chamber=H&SPick=20130&cosponId=14261> (declaring that Pennsylvania's legislation would "simply require health care practitioners to provide complete information to women who receive a prenatal diagnosis for Down syndrome so that they are better informed with regard to the positive outcomes of giving birth to a" child with this condition).

found it necessary to pass such legislation can be read as an indictment of the current state of prenatal genetic counseling. Moreover, the ideological diversity of the states passing such laws, coupled with the bipartisan support they have received, indicates that underinformed terminations for fetal anomaly are a significant concern whether one is pro-choice or pro-life.

Though it is still too early to determine if state legislation in this area will achieve its overall objectives, even assuming perfect implementation, there remain a number of concerns. First and foremost, there are still 39 states—covering roughly 75% of the population¹³⁰—with no pro-information legislation to supplement the underfunded and ineffective PPDKAA. Women in these states must therefore rely on individual research and whatever information their health care providers deem appropriate in determining whether to proceed with their pregnancies. Second, six of the eleven states that have passed pro-information legislation address it exclusively to Down syndrome and are silent with respect to other prenatally and postnatally diagnosed conditions (recall that a seventh, Kentucky, addresses just Down syndrome and spina bifida). This means that in these states there is no legislative mandate to provide improved information for other fetal abnormalities such as cystic fibrosis, sickle-cell anemia, neural tube defects, or syndromes such as Edwards, Patau, Angelman, or Beckwith-Wiedemann—the diagnosis of any one of which forces a pregnant woman to grapple with emotional, ethical, and psychological concerns similar to learning her fetus has Down syndrome. Finally, given the overall objective of delivering much-needed information to women deciding how to address a fetal abnormality, it is troubling that some states make the provision of the information discretionary rather than mandatory.¹³¹

In sum, despite the headway made by these eleven states, there remain significant gaps in existing pro-information legislation at the state level, and we are only beginning to scratch the surface of delivering this crucial information nationwide. While it should be taken as a positive first step that states are increasingly sensitive to these concerns, the

¹³⁰ See 2014 Population Estimates, Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2014, U.S. CENSUS BUREAU, http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2014_PEPANNRES&src=pt (last visited Feb. 21, 2016) (showing that the aggregate population of the eleven states having passed pro-information is just over 80 million, and the population of the United States as a whole is near 309 million).

¹³¹ See, e.g., MD. CODE ANN., HEALTH-GEN. § 20-1502(c)(1) (2014) (“On receipt of a positive test result . . . a health care facility of health care provider *may* provide to the expectant parent . . . written information provided or made available by . . . this section.”) (emphasis added); VA. CODE ANN. § 54.1-2403.01(B) (2008) (requiring that medical information be distributed upon discovering a prenatally diagnosed condition but leaving the provision of information regarding education and support programs).

pressing need for more effective and further reaching pro-information legislation will become readily apparent in the near future, when prenatal genetic analysis becomes normalized and the concomitant number of detected fetal abnormalities begins to skyrocket. The following Part describes two key factors contributing to the emergent growth in prenatal genetic analysis and discusses the corresponding increase in the need for improved dissemination of information relating to fetal abnormalities.

IV. THE EMERGENT GROWTH IN PRENATAL GENETIC ANALYSIS

Though many pregnant women opt out of prenatal genetic screening and less than 2% nationwide undergo prenatal testing,¹³² current rates of genetic analysis will rise sharply in future years due to the combination of two recent developments. First is the passage and ongoing implementation of the Patient Protection and Affordable Care Act (ACA).¹³³ Among its numerous mandates, the ACA enlarges the number of moderate-income women who are eligible for Medicaid—a federal/state medical insurance program that in the majority of states provides free or low-cost prenatal genetic screening and testing.¹³⁴ The ACA also requires that all health insurance plans, public or private, provide certain essential benefits, and includes maternity and newborn care—which may include prenatal genetic screening and testing—among them. Lastly, the ACA makes mandatory coverage of certain preventive care for women, which will include prenatal genetic screening and testing in many states.

The second recent development is the evolving manner in which pregnant women can learn of prenatal genetic abnormalities. Whereas currently the prevailing forms of genetic testing—CVS and amniocentesis—are invasive, painful, and potentially fatal to the fetus, cutting-edge methods of Noninvasive Prenatal Diagnosis (NIPD) have emerged in recent years and are quickly being adopted in clinical settings. These methods will soon allow women to screen, and perhaps test, for a host of fetal genetic abnormalities with unprecedented accuracy by providing a small sample of maternal blood in the early stages of pregnancy, without any potential of harming the fetus. As NIPD becomes a normalized component of prenatal care in the coming years, more women will learn of fetal abnormalities early in their pregnancies, thereby growing the population of expectant mothers in need of improved coun-

¹³² Greely, *supra* note 18, at 289.

¹³³ See 42 U.S.C. §§ 18001–18121 (2012).

¹³⁴ USHA RANJIT ET AL., STATE MEDICAID COVERAGE OF PERINATAL SERVICES: SUMMARY OF STATE SURVEY FINDINGS 3 (2009), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8014.pdf> (finding that “36 states and DC cover genetic screening services, 40 states and DC cover chorionic villus sampling (CVS) and 42 and DC cover amniocentesis”).

selling and better information. The following sections provide a brief overview of these recent developments and their implications.

A. *The Affordable Care Act*

1. Medicaid Expansion

The Affordable Care Act drastically increases the number of Americans who are eligible for Medicaid.¹³⁵ Among those newly covered under the Medicaid expansion and other provisions of the ACA will be approximately thirteen million women of childbearing age.¹³⁶ These new enrollees will in large measure have free or low-cost access to prenatal genetic screening, testing, or both. A recent Kaiser Family Foundation study found that Medicaid programs in 36 States and the District of Columbia cover genetic screening, 40 States and the District cover chorionic villus sampling (CVS), and 42 states and the District cover amniocentesis.¹³⁷ The expansion of the pool of women with free or heavily subsidized access to genetic screening and testing will result in an inevitable rise in the number of those taking advantage of these diagnostic tools, and a concomitant increase in the number of prenatal genetic abnormalities that are identified.

2. Defining “Essential Health Benefits”

Perhaps more important than the expansion of Medicaid is the ACA’s delineation of the “essential health benefits” all health insurance plans must provide with limited cost-sharing (such as co-pays, co-insurance, and deductibles).¹³⁸ Among the ten essential health benefits (EHBs) is “Maternity and newborn care.”¹³⁹ Though the ACA does not explicitly reference prenatal genetic screening or testing as an essential health benefit, the regulations for defining EHBs permit individual states

¹³⁵ THE KAISER COMMISSION ON MEDICAID AND THE UNINSURED, *MEDICAID: A PRIMER* 11 (2013), <https://kaiserfamilyfoundation.files.wordpress.com/2010/06/7334-05.pdf> (“The ACA expands Medicaid by establishing a new Medicaid eligibility group for adults under age 65 with income at or below 138% [of the federal poverty level]. These adults make up about half the uninsured. Accounting for enrollment among adults who gain Medicaid eligibility due to the expansion, as well as increases in participation among children and adults eligible for Medicaid prior to the ACA, Medicaid enrollment is expected to increase by 21.3 million by 2022.”).

¹³⁶ Rebouché & Rothenberg, *supra* note 32, at 994.

¹³⁷ RANJI ET AL., *supra* note 134, at 14. In addition, one study found that Medicaid in 24 states covers prenatal genetic counseling. *See* COMM. ON PREVENTIVE SERVS. FOR WOMEN, INST. OF MED., *CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS* 61 (2011) [hereinafter *CLOSING THE GAPS*], http://www.nap.edu/openbook.php?record_id=13181.

¹³⁸ 42 U.S.C. § 18022 (2012).

¹³⁹ 42 U.S.C. § 18022(b)(1)(D) (2012).

to determine their scale and scope,¹⁴⁰ through the selection of currently-existing benchmark insurance plans.¹⁴¹

All state benchmark plans currently provide “prenatal and postnatal care” as an EHB.¹⁴² And though the inclusion of genetic screening, testing, or both in this category is unclear with respect to many states, the benchmark plans of California¹⁴³ and Hawaii¹⁴⁴ specifically include these diagnostic tools. Other states having benchmark plans that are silent in this regard require that insurers cover prenatal genetic screening and testing by statute.¹⁴⁵ Though it remains to be seen how many state benchmark plans will ultimately define covered “prenatal and postnatal care” to include prenatal genetic screening, testing, or both,¹⁴⁶ there can be no doubt that there will be an overall increase in covered prenatal care under the Affordable Care Act.¹⁴⁷ It follows that the number of non-

¹⁴⁰ 45 C.F.R. § 156.100 (2013); *see also* Robert Pear, *Health Care Law Will Let States Tailor Benefits*, N.Y. TIMES, Dec. 16, 2011, at A1.

¹⁴¹ 45 C.F.R. § 156.100(a) (2013). The default for those states that do not select benchmark plans is the “the largest plan by enrollment in the largest product by enrollment in the State’s small group market.” 45 C.F.R. § 156.100(c) (2013).

¹⁴² *See Information on Essential Health Benefits (EHB) Benchmark Plans*, CTRS. FOR MEDICAID & MEDICARE SERVS., www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html (last visited Feb. 21, 2016).

¹⁴³ CTRS. FOR MEDICAID AND MEDICARE SERVS., CALIFORNIA EHB BENCHMARK PLAN 7–8, <https://www.cms.gov/CCIIO/Resources/Data-Resources/Downloads/Updated-California-Benchmark-Summary.pdf> (last visited Feb. 9, 2016).

¹⁴⁴ CTRS. FOR MEDICAID AND MEDICARE SERVS., HAWAII EHB BENCHMARK PLAN 6, 9, <https://www.cms.gov/CCIIO/Resources/Data-Resources/Downloads/Updated-Hawaii-Benchmark-Summary.pdf> (last visited Feb. 9, 2016).

¹⁴⁵ *See, e.g.*, WASH. REV. CODE ANN. § 48.44.344 (West 2013) (“[E]very group health care services contract entered into or renewed that covers hospital, medical, or surgical expenses on a group basis, and which provides benefits for pregnancy, childbirth, or related medical conditions to enrollees of such groups, shall offer benefits for prenatal diagnosis of congenital disorders of the fetus by means of screening and diagnostic procedures during pregnancy to such enrollees when those services are determined to be medically necessary”); N.M. STAT. ANN. § 59A-23-6.1 (LexisNexis 2013) (“A blanket or group health policy, health care plan or certificate of health insurance that is delivered, issued for delivery or renewed in the state shall provide coverage for an alpha-fetoprotein IV screening test for pregnant women, generally between sixteen and twenty weeks of pregnancy, to screen for certain genetic abnormalities in the fetus.”); *see also* Rebouché & Rothenberg, *supra* note 32, at 997 (inferring that Alabama, Arkansas, Minnesota, New Hampshire, and Wisconsin cover prenatal genetic testing and screening because they mandate that insurers cover all “medically necessary” prenatal care).

¹⁴⁶ There also remains the legislative option noted above. *See supra* note 145 and accompanying text.

¹⁴⁷ *See, e.g.*, Adam Sonfield & Harold A. Pollack, *The Affordable Care Act and Reproductive Health: Potential Gains and Serious Challenges*, 38 J. HEALTH POL. POL’Y & L. 373, 374 (2013) (“The [ACA] has the potential to have a positive impact on reproductive health in at least three ways: (1) increasing the number of women and men with insurance coverage; (2) increasing the value of insurance coverage for addressing reproductive health; and (3) improving access to reproductive health services and information more generally.”); Rebekah E. Gee & Sara Rosenbaum, *The Affordable Care Act: An Overview for Obstetricians and Gynecologists*, 120 OBSTETRICS & GYNECOLOGY 1263, 1265 (2012) (“The Act’s emphasis on enhanced

Medicaid insureds who have low-cost access to such care will undoubtedly increase, further expanding the number of prenatal genetic diagnoses.

3. Preventive Care Mandate

Finally, access to prenatal genetic screening and testing could also be reasonably construed as a matter of right under the ACA's preventive care mandate. Pursuant to the Act, all insurers must provide minimum coverage without cost sharing (co-pays, co-insurance, and deductibles) for certain preventive services.¹⁴⁸ Included within this minimum coverage is, with respect to women, "such preventive care and screenings . . . as provided for in comprehensive guidelines supported by the Health Resources and Services Administration [HRSA]."¹⁴⁹ The Department of Health and Human Services (DHHS) regulations accompanying this statutory provision further specify the coverage insurers must provide free of charge.¹⁵⁰ They require that all plans cover "evidence-informed preventive care and screenings" for women, again as determined by "guidelines supported by the [HRSA],"¹⁵¹ a division of DHHS.

In crafting the relevant guidelines, DHHS commissioned a study from the Institute of Medicine (IOM), a third-party organization. The IOM submitted its recommendations in a report titled *Clinical Preventive Services for Women: Closing the Gaps*.¹⁵² Most relevant among the many conclusions found in its 236-page report, the IOM recommended "at least one well-woman preventive care visit annually for adult women to obtain the recommended preventive services, including preconception and prenatal care."¹⁵³ It further recommended that covered prenatal visits be required to incorporate a number of "tests and procedures," including "screening for . . . genetic or developmental conditions."¹⁵⁴ Though

primary care can be expected to result in important opportunities for broader access to obstetricians and gynecologists. As a result, the Act may create an unprecedented demand for care. Insurance expansions mean that millions of American women now will be able to establish a regular source of primary and preventive care."); ALISON CUELLAR ET AL., OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING AND EVALUATION, DEP'T OF HEALTH & HUMAN SERVS., THE AFFORDABLE CARE ACT AND WOMEN 2 (2012) ("Eliminating such barriers as copayments, co-insurance, and deductibles will increase access to services that improve the health of women and their children.").

¹⁴⁸ 42 U.S.C. § 300gg-13(a) (2012).

¹⁴⁹ *Id.* § 300gg-13(a)(4).

¹⁵⁰ *See* 45 C.F.R. § 147.130 (2013).

¹⁵¹ 45 C.F.R. § 147.130(a)(1)(iv) (2013) ("With respect to women . . . evidence-informed preventive care and screenings provided for in binding comprehensive health plan coverage guidelines supported by the Health Resources and Services Administration.").

¹⁵² CLOSING THE GAPS, *supra* note 137.

¹⁵³ *Id.* at 12.

¹⁵⁴ *Id.* at 133; *see also id.* at 56–57 (endorsing the National Business Group on Health's list of 46 recommended benefits directly relevant to women that should be included in all

not endorsing prenatal genetic testing or screening directly, the HRSA has indicated that its interpretation of the preventive care mandate with respect to women is in lock-step with the IOM report.¹⁵⁵

In short, both the IOM and HRSA, the agency authorized to issue guidelines under the ACA, consider prenatal genetic analysis of some form to fall under the Affordable Care Act's "preventive care and screening" mandate. Because the ACA relies on these two agencies (either directly or indirectly) to interpret its language, it is reasonable to infer that the Act mandates that many, if not all, insured expectant women have access to prenatal testing, screening, or both. Acknowledging that Courts will vary in resolving this question going forward, it is safe to assume that in at least some jurisdictions, prenatal genetic screening, testing, or both will become the right of any insured pregnant women, rather than the privilege of those with superior insurance or the means to pay for it.

* * *

The combination of the Affordable Care Act's expanding Medicaid coverage, defining maternity and newborn care as an essential health benefit, and mandating that certain preventive care be covered by all insurers will result in an unprecedented increase in the number of women who have access to free or low-cost prenatal genetic screening, testing, or both. Though it is unclear how each of these measures will ultimately play out, there can be no doubt that there will be a significant increase in access to prenatal genetic analysis in many jurisdictions, which will act to exacerbate the need for improved support in navigating the ethical challenges inherent in the discovery of a prenatal genetic abnormality and the subsequent decision whether to terminate.

B. The Emergence of NIPD

Separate and apart from the increased need for genetic counseling and improved information regarding fetal abnormalities resulting from Affordable Care Act's expansion of coverage is the impact that emerging methods of Noninvasive Prenatal Diagnosis (NIPD) will have on pregnant women. The varying methods of NIPD are all built upon the 1997 discovery that fetal cell-free DNA (cfDNA) circulates in, and can be ex-

health plans, among them: "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.").

¹⁵⁵ *Women's Preventive Services Guidelines*, HEALTH RES. & SERVS. ADMIN., www.hrsa.gov/womensguidelines/ (last visited Feb. 21, 2016) ("HRSA is supporting the IOM's recommendations on preventive services that address health needs specific to women and fill gaps in existing guidelines.").

tracted from, maternal plasma.¹⁵⁶ Technicians can thus obtain and analyze fetal genetic material from a maternal blood sample,¹⁵⁷ as early as the tenth week of gestation.¹⁵⁸ Once separated from the plasma and isolated, cfDNA can be sequenced and assessed for risk through use of an algorithm.

The accuracy of NIPD is extraordinary. In a recent study of 15,841 women at 35 international centers, cfDNA analysis detected 100% of fetuses having Trisomy 21, or Down syndrome, while standard screening (which included serum screening and testing for nuchal translucency) detected only 78.9%.¹⁵⁹ Perhaps more important, cfDNA analysis produced just 9 false positives for Trisomy 21 (.06%), as opposed to 854 false positive results (5.4%) on standard screening.¹⁶⁰ In the same study, cfDNA also outpaced standard screening in identifying Trisomy 18, or Edwards syndrome. Of the 10 cases in the study, cfDNA identified 9, with one false positive, while standard screening identified 8, with 49 false positive results.¹⁶¹ And for Trisomy 13, Patau syndrome, cfDNA identified both cases (with one false positive), while standard screening identified one (with 28 false positives).¹⁶²

The accuracy of cfDNA analysis in this study is not anomalous¹⁶³—cfDNA is clearly superior to standard screening in relation to certain fetal abnormalities, particularly in terms of false positives.¹⁶⁴ The current question, given cfDNA’s high rate of accuracy, is to what extent it may or should be relied upon in *diagnosing* fetal abnormalities. In other words, where does cfDNA fit within the current menu of fetal genetic

¹⁵⁶ See Anita de Jong et al., *Non-invasive Prenatal Testing: Ethical Issues Explored*, 18 EUR. J. HUM. GENETICS 272, 272 (2010).

¹⁵⁷ Devers et al., *supra* note 5, at 292.

¹⁵⁸ See, e.g., Mary E. Norton et al., *Non-Invasive Chromosomal Evaluation (NICE) Study: Results of a Multicenter Prospective Study for Detection of Fetal Trisomy 21 and Trisomy 18*, 207 AM. J. OBSTETRICS & GYNECOLOGY 137.e1, 131.e2 (2012) (requiring that study participants be at a gestational age greater than or equal to ten weeks); Andrew B. Sparks et al., *Noninvasive Prenatal Detection and Selective Analysis of Cell-Free DNA Obtained from Maternal Blood: Evaluation for Trisomy 21 and Trisomy 18*, 206 AM. J. OBSTETRICS & GYNECOLOGY 319.e1, 319.e2 (2012) (describing a study requiring that participants be at a gestational age greater than or equal to ten weeks).

¹⁵⁹ Mary E. Norton et al., *Cell-free DNA Analysis for Noninvasive Examination of Trisomy*, 371 NEW ENG. J. MED. 1589, 1593 (2015).

¹⁶⁰ *Id.*

¹⁶¹ *Id.* at 1594.

¹⁶² *Id.*

¹⁶³ See, e.g., Norton et al., *supra* note 158, at 137.e4–e5 (identifying 100% of Trisomy 21 cases with a false positive rate of .01% and 97.4% of Trisomy 18 cases with a false positive rate of .07%); Sparks et al., *supra* note 158, at 319.e4 (detecting 100% of Trisomy 21 and Trisomy 18).

¹⁶⁴ See Norton et al., *supra* note 159, at 1595 (“The false positive rate of cfDNA testing was nearly 100 times lower than that of standard screening” for Trisomy 21).

analysis tools available to pregnant women?¹⁶⁵ One study hypothesized five possibilities: 1) “as an additional test to improve overall risk assessment,” 2) “as an intermediate test between risk assessment and invasive diagnostic testing for high-risk pregnancies,” 3) “as a replacement for current risk-assessment tests,” 4) “as a replacement for current invasive diagnostic tests,” or 5) “as a replacement for both risk-assessment and diagnostic tests.”¹⁶⁶

NIPD has already served functions one through three, acting as a screening mechanism deployed with or in lieu of traditional risk-assessment in advance of diagnostic genetic testing (usually by way of CVS or amniocentesis). It now appears that we are edging ever closer to the day when cfDNA will serve the fourth and fifth functions, replacing invasive diagnostic testing and, perhaps, becoming the standard method of risk assessment.¹⁶⁷ Should cfDNA analysis of a small sample of maternal blood emerge as a standard of prenatal care and its results understood as diagnostic, it would mark a radical shift.

California, which has a statewide prenatal genetic screening and testing program covering blood tests, amniocentesis, chorionic villus sampling, and diagnostic ultrasound,¹⁶⁸ provides a useful basis for extrapolating the potential impact of normalizing diagnostic cfDNA analysis. There, roughly 2/3 of pregnant women undergo noninvasive prenatal genetic screening.¹⁶⁹ As Stanford Law School professor Henry Greely calculated in *Nature*, if the same proportion of women were to opt for noninvasive prenatal genetic testing nationwide, the number of fetuses tested annually would jump from fewer than 100,000 to roughly 3 million.¹⁷⁰ This thirty-fold increase would produce a heretofore unimagin-

¹⁶⁵ See Norton et al., *supra* note 158, at 137.e7 (noting that “the place of this technology remains uncertain” and discussing the potential use of cfDNA analysis as “an intermediate screening tool” or “an alternative to invasive diagnostic testing”).

¹⁶⁶ De Jong et al., *supra* note 156, at 273 (citing CAROLINE WRIGHT, CELL-FREE FETAL NUCLEIC ACIDS FOR NON-INVASIVE PRENATAL DIAGNOSIS (2009), http://www.phgfoundation.org/download/ffdna/ffdna_report.pdf).

¹⁶⁷ See, e.g., Sparks et al., *supra* note 158, at 319.e8–e9 (observing that should cfDNA analysis become cheaper and more accessible, it may replace the “myriad screening and testing options today,” save ultrasound); Elisavet A. Papageorgiou et al., *Fetal-specific DNA Methylation Ratio Permits Noninvasive Prenatal Diagnosis of Trisomy 21*, 17 NAT. MED. 510, 513 (2011) (observing that, given recent advances in cfDNA analysis, NIPD may be “employed in the routine practice of all diagnostic laboratories and be applicable to all pregnancies” in diagnosing Trisomy 21, thereby avoiding the “risk of miscarriages of normal pregnancies caused by current, more invasive procedures” and speculating that it can potentially be employed to detect anomalies in chromosomes 13, 18, X, and Y).

¹⁶⁸ See Cal. Health & Safety Code § 125050 (2015).

¹⁶⁹ Greely, *supra* note 18, at 290.

¹⁷⁰ *Id.*

able wave of women struggling to understand their tests, the implications of a positive result, and how to proceed.¹⁷¹

C. *Implications on the Future of Prenatal Diagnosis*

Taken together, the expanded coverage of prenatal genetic screening and testing under the ACA and the emergence of NIPD as a potentially normalized diagnostic component of prenatal care will increase the population of women who undergo prenatal genetic analysis and introduce a new population to the vexing ethical dilemma of whether to terminate a genetically anomalous fetus. As shown above, genetic terminations have far-reaching psychological consequences for the mother, her partner, and living children, and while federal and state legislative efforts to provide women with adequate information and access to support during the decisionmaking process are notable in their existence, they do not go nearly far enough in scale or in scope. Given the shortcomings of prenatal genetic counseling in its current form, one can only imagine how ineffective it will become under the increased number of pregnant women in need of its services pursuant to the ACA and the emergence of NIPD. The following Part offers suggestions for how better to support and deliver information to the growing population of women requiring prenatal genetic counseling, with an emphasis on alleviating the psychological impacts of underinformed genetic terminations.

V. A NEW LEGISLATIVE AND COUNSELING FRAMEWORK

The proposals set forth in this Part are built upon the following points that have been established above. Whether their main point of contact is a genetic counselor or other health care professional, women learning of a genetic fetal abnormality are presented with selective, inadequate information that they often do not understand. This presentation of information, combined with genetic counseling that is often directive in practice, leads to underinformed terminations for fetal abnormalities. The resultant genetic terminations are traumatic major life events that produce high rates of grief, depression, and post-traumatic stress, sometimes for years. And due to recent legislative and technological developments likely to normalize prenatal genetic analysis, there will be an

¹⁷¹ That women undergoing diagnostic NIPD would on average learn of their fetal anomaly earlier in pregnancy than under the currently prevailing methods of genetic testing is immaterial insofar as they will still have to grapple with the dilemma of whether to terminate a wanted pregnancy and deal with the adverse consequences should they choose to do so. See RING-CASSIDY & GENTLES, *supra* note 70, at 161 (noting that termination due to a fetal abnormality is “often a shattering experience” in “both ‘early’ as well as ‘late’ genetic abortions”) (citations omitted). The authors add, “there may be instances in which an early abortion may present more difficulties than a later abortion.” *Id.*

exacerbation of each of these problems in the coming years. Lastly, though Congress and state legislatures have attempted to provide women with improved medical and support information so as to help them make better-informed choices, existing federal and state legislation is inadequate due to the combination of limited funding, drafting oversights, and limitations in scale and scope.

A. *Conceptualizing Model Legislation*

Addressing these problems requires both legislation that will promote the dissemination of adequate information to expecting parents and the establishment of best practices for healthcare professionals delivering the message. Though the federal PPDCAA has been ineffective due to underfunding, it contains key elements of a model pro-information legislation.¹⁷² Addressed to all prenatally and postnatally diagnosed conditions rather than just Down syndrome, the PPDCAA calls for the provision of “[u]p to date, evidence-based, written information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.”¹⁷³ Requiring that the “range of outcomes” be presented is most important, as women undergoing prenatal genetic counseling currently receive selective information about fetal anomalies and their possible outcomes, which is informed by both the nature of the anomaly and various cultural, educational, and socioeconomic factors.¹⁷⁴

The PPDCAA also mandates the provision of “[c]ontact information regarding support services,” including information hotlines, “resource centers or clearinghouses, national and local peer support groups, and other education and support programs”¹⁷⁵ Most important here are the support services. As will be discussed below, one of the most consistent findings in studies of women who have terminated due to a fetal abnormality is that they often lack adequate support, and lack of support during both the decision-making process and after termination is a significant risk factor for grief, depression, and post-traumatic stress.

By addressing an array of conditions, providing information about the range of outcomes for prenatal genetic diagnoses, and endeavoring to connect women with much-needed support services, the PPDCAA

¹⁷² Indeed, the National Down Syndrome Society’s model prenatal testing legislation, part of its “Pro-Information State Law Toolkit,” tracks the PPDCAA closely. *Compare* Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008), with *Sample Prenatal Testing Information Model Legislation*, NAT’L DOWN SYNDROME SOC’Y, <http://www.ndss.org/PageFiles/5025/Bill%20H03825.pdf> (last visited Feb. 21, 2016) [hereinafter *Model Legislation*].

¹⁷³ 42 U.S.C. § 280g-8(c)(1)(A) (2012).

¹⁷⁴ See *supra* notes 53–54 and accompanying text.

¹⁷⁵ 42 U.S.C. § 280g-8(c)(1)(B).

touches on the main concerns that are key in creating model legislation. But the legislation is not without its faults. Its main problem (other than underfunding) is that it requires that this information be provided “to health care providers of parents who receive a prenatal or postnatal diagnosis,”¹⁷⁶ rather than the parents themselves. It is likely that many providers already have access to much of this information; the problem is that parents are not receiving it, and the PPDCAA does nothing in this regard. The National Down Syndrome Society’s model legislation,¹⁷⁷ as well as the legislation that has been enacted in several states,¹⁷⁸ corrects this shortcoming by requiring that parents be provided with relevant medical and contact information. Future legislation should follow these states by ensuring that parents, and not just their caregivers, receive this information.

Borrowing from Kansas’s Prenatal and Postnatal Diagnosed Conditions Awareness program could also help the PPDCAA serve as a better model. Kansas’s statute grants the Secretary of the Department of Health authority to grant and oversee certain programs relating to fetal abnormalities. Though most are familiar, one stands out: “the establishment of a network of local registries of families willing to adopt newborns with Down syndrome or other prenatally or postnatally diagnosed conditions and links to adoption agencies willing to place babies with [these] conditions with families willing to adopt.”¹⁷⁹ This provision, unique to Kansas, can serve an important function for women who believe they are unprepared to raise a child with a fetal abnormality, but at the same time do not believe termination is the right choice for them.

Be it state or federal, effective legislation must incorporate each of these elements, and the medical, range of outcomes, and support (including peer support and adoption options) information gathered about each prenatally or postnatally diagnosed condition must be provided to women rather than just their providers. That said, the efficacy of even the finest pro-information legislation will ultimately turn on its ground-level implementation. The following section offers suggestions for how to translate broad legislative mandates regarding prenatal and postnatal diagnoses into effective treatment, from when women first learn of the possibility of a fetal abnormality through after termination or delivery.

¹⁷⁶ 42 U.S.C. § 280g-8(c)(1).

¹⁷⁷ *Model Legislation*, *supra* note 172, § 1(a) (requiring that facilities, physicians, health care, providers, nurse midwives, or genetic counselors “provide the expectant or new parent” with medical and support information).

¹⁷⁸ *See, e.g.*, OHIO REV. CODE ANN. § 3701.69(B) (2014) (requiring that health care professionals and facilities provide patients with medical and support information); 35 PA. CONS. STAT. ANN. § 6243(a) (2014) (same); FLA. STAT. § 383.141(2) (2012) (same).

¹⁷⁹ KAN. STAT. ANN. § 65-1,259(a)(2)(D) (2013).

B. Keys to Effective Implementation

Best practices for treating women carrying genetically anomalous fetuses do not require legislation. Indeed, facilities such as the Special Delivery Unit at Children's Hospital of Philadelphia, which deals exclusively with fetuses having prenatally diagnosed conditions, already devote a great deal of attention to providing adequate support. Nonetheless, legislation requiring that women be provided access to educational and support services will require radical changes for most hospitals, and those seeking to abide by such legislation will be left wondering how best to educate and support women so as to mitigate negative psychological outcomes.

1. Support During Decision-making

Though there is little evidence regarding the efficacy of interventions on patterns of grieving,¹⁸⁰ as a point of departure health care professionals should recognize that termination due to a fetal anomaly, unlike other abortions, is a major life event for nearly all women¹⁸¹ and experienced by both men and women as a trauma rather than a loss.¹⁸² Conceptualizing a genetic termination as a unique trauma informs how women who learn of a fetal abnormality should be treated from the outset. Caregivers should be frank in discussing potential outcomes with their patients, offering guidance and psychological support during the decision-making process so as "to avoid impulsive and not fully internalized decisions."¹⁸³ In addition to describing the challenges of raising a child born with a potential disability, caregivers should also explain that grief, depression, and post-traumatic stress are distinct possibilities should they choose to terminate. Though such information might strike some as coercive, it is essential to providing the mother with the ability to make an informed choice.¹⁸⁴ Indeed, painting a more complete picture of potential outcomes of both termination and delivery would constitute a meaningful step in moving prenatal genetic counseling closer to the elusive goal of nondirectiveness.¹⁸⁵

¹⁸⁰ Kersting & Wagner, *supra* note 69, at 191.

¹⁸¹ See *supra* notes 68–71 and accompanying text.

¹⁸² See *supra* note 89 and accompanying text.

¹⁸³ Korenromp et al., *supra* note 68, at 259.

¹⁸⁴ RING-CASSIDY & GENTLES, *supra* note 70, at 167 ("For an informed choice to be truly available pregnant women and their partners need to be told about the possible impact of abortion on them and their other children, and they also need to have information about the care of children with special needs."); see also McCoyd, *supra* note 71, at 45 (noting with respect to genetically anomalous fetuses that "[p]ain would exist whether [parents] terminate or whether they had a baby who then had to cope with medical and social challenges").

¹⁸⁵ See *supra* notes 41–55, 61 and accompanying text.

The exchange of information should be a two-way street; the ultimate objective between woman and caregiver should be to achieve “mutual satisfaction with the information provided.”¹⁸⁶ Expecting mothers should thus have access to frequent consultation—be it with a gynecologist, geneticist, genetic counselor, social worker, or psychiatrist—not only after terminating (as will be discussed below), but when considering termination as well.¹⁸⁷ Given that lack of information *ex ante* is a persistent concern in relation to genetic terminations,¹⁸⁸ an open, iterative dialogue focused on providing the mother with information and reassurance would go a long way toward fostering informed choices and better psychological outcomes.¹⁸⁹

2. Support After Termination

Even with a better understanding of potential outcomes and increased access to supportive health care providers, many women will still choose to terminate their genetically anomalous fetuses. It is these women who stand to benefit most from a more particularized understanding of genetic terminations that acknowledges the significant risk of psychological outcomes they entail. Current standards of care—pursuant to which there are frequently few formal post-termination supports available other than a post-delivery or post-surgical exam¹⁹⁰—are insufficient.¹⁹¹ What is needed is a well-organized¹⁹² and multidisciplinary¹⁹³ plan of action focusing on the care, support, and understanding that women terminating for a fetal abnormality have identified as being most important to them.¹⁹⁴

Because routinely given preventative interventions addressing bereavement or traumatic events have not proved effective,¹⁹⁵ the contours of the support each woman receives should vary based on her circumstances. In all cases, however, subsequent supportive interventions—be

¹⁸⁶ See Nina Asplin et al., *Pregnancy Termination due to Fetal Abnormality: Women's Reactions, Satisfaction and Experiences of Care*, 30 *MIDWIFERY* 620, 625 (2014).

¹⁸⁷ Korenromp et al., *supra* note 86, at 160.e6.

¹⁸⁸ See *supra* Part I.B; see also RING-CASSIDY & GENTLES, *supra* note 70, at 167 (“Couples are not prepared for the depression and guilt that frequently ensue. Nor are they usually informed about the help that is available for raising children with special needs.”).

¹⁸⁹ Korenromp et al., *supra* note 86, at 160.e6.

¹⁹⁰ McCoyd, *supra* note 71, at 45.

¹⁹¹ Asplin et al., *supra* note 186, at 625.

¹⁹² *Id.* at 625 (“Well-organised follow-up care is essential after termination due to a fetal malformation.”).

¹⁹³ Korenromp et al., *supra* note 86, at 160.e6.

¹⁹⁴ Asplin et al., *supra* note 186, at 625; see also McCoyd, *supra* note 71, at 46 (noting that women “benefit from health care providers who assure adequate formal and informal support resources and who allow them to process their feelings, expectations and dilemmas with an empathetic manner”).

¹⁹⁵ Korenromp et al., *supra* note 86, at 160.e6.

they by a gynecologist, geneticist, genetic counselor, social worker, or psychiatrist—should reassure patients that any feelings of grief, depression, and trauma they are experiencing are in no way unusual.¹⁹⁶ Access to support groups, as referenced in the above discussion of model legislation,¹⁹⁷ should also be made generally available, provided that, where possible, they be comprised of individuals who have also decided to undergo a genetic termination, rather than those who have experienced other traumatic events.¹⁹⁸

Beyond some form of empathetic and reassuring follow-up care and access to support groups, women suffering from severe symptoms such as post-traumatic stress should have access to ongoing psychotherapeutic monitoring.¹⁹⁹ This intervention is beneficial not only to the mother who has terminated, but also to any living children, whose development can be negatively impacted by maternal post-traumatic stress.²⁰⁰ Formalized post-termination support can also benefit male partners, who may lack informal peer support due to both prevailing gender norms and the rightful emphasis placed on their partner's experience.²⁰¹

Promoting the mental well-being of male partners can benefit women as well due to the “mutual influence between the partners in the process of grieving.”²⁰² Lack of partner support is a frequently identified risk factor for significant post-termination psychological outcomes.²⁰³ The obvious corollary is that good adjustment to a genetic termination “is dependent on the level of support [women] perceive from their partners.”²⁰⁴ Accordingly, in its ideal form, whatever counseling is indicated

¹⁹⁶ *Id.*

¹⁹⁷ See *supra* note 175 and accompanying text.

¹⁹⁸ McCoyd, *supra* note 71, at 45 (“Women benefit from support where the whole story can be told, particularly in support groups designed for couples who have this experience.”); Marijke J. Korenromp et al., *Maternal Decision to Terminate Pregnancy After a Diagnosis of Down Syndrome*, 196 AM. J. OBSTETRICS & GYNECOLOGY 149, 150 (2007) (“Counseling should include the presentation of information about professionally run support groups or self help groups with other parents in similar situations.”).

¹⁹⁹ Kersting et al., *supra* note 68, at 200; see also Asplin et al., *supra* note 186, at 625 (“Some patients can also benefit from being referred to a psychologist for evaluation/treatment.”).

²⁰⁰ Kersting et al., *supra* note 68, at 200.

²⁰¹ France et al., *supra* note 75, at 31; see also *supra* notes 93–98 and accompanying text (noting that men experience grief, depression, and post-traumatic stress, but often have trouble accessing emotional support and tend to suppress their emotions).

²⁰² Korenromp et al., *supra* note 85, at 1232.

²⁰³ See Korenromp et al., *supra* note 68, at 255 (“[W]omen who reported that they had experienced little support from their partners had the most unfavourable scores on the psychological inventories.”); Korenromp et al., *supra* note 85, at 1232 (noting in a study of 151 couples that “women in particular showed lower levels of grief and depression when they had perceived good support of their partner”).

²⁰⁴ Korenromp et al., *supra* note 85, at 1232.

should involve both partners as much as possible.²⁰⁵ As one study summarized, “Both partners have to be equally involved in the counseling. Both are parents of the child . . . the choice not to continue the pregnancy is their joint decision, and both suffer psychological distress.”²⁰⁶ Though currently uncommon and not without its challenges,²⁰⁷ widespread inclusion of male partners in post-termination counseling would be an important step in alleviating psychological outcomes for father and mother alike.

In sum, counseling during the decisionmaking process should candidly acknowledge the potential psychological downsides of terminating on genetic grounds. There should also be open channels of communication during this period in order to ensure mutually satisfactory sharing of information. All women who terminate their pregnancies should receive some form of counseling (rather than just medical follow up) informed by reassurance, empathy, care, support, and understanding, and should also have access to group therapy with others who have terminated on genetic grounds. Those requiring it, male and female alike, should have access to subsequent psychological treatment. And male partners should generally be included in all forms of post-termination support.

Notwithstanding that there could be other possible interventions—such as a special emphasis on other risk factors like low levels of education²⁰⁸ or support catering to children—embracing this approach to applying pro-information legislation relating to prenatally and postnatally diagnosed conditions will address a large majority of the concerns relating to genetic terminations raised in this Article. Though ideal legislation with perfect, individualized implementation is a far-fetched aspiration, widespread clinical application of any of these suggestions has the potential to alleviate the severe psychological impacts of genetic terminations for many women. Ultimately, what is most important is that policymakers better understand the unique nature of this problem and take steps to address it more effectively as it grows in scale and scope in the upcoming years.

²⁰⁵ Kersting & Wagner, *supra* note 69, at 191 (recommending that intervention approaches “should involve male partners, including them in psychotherapy and ensuring an ongoing dialogue between the grieving parents”); Korenromp et al., *supra* note 85, at 1232 (emphasizing the “importance of involving both parents in the counselling”); Korenromp et al., *supra* note 198, at 150 (noting that it is “essential to involve always both partners in the counseling” after a Down syndrome diagnosis).

²⁰⁶ Korenromp et al., *supra* note 92, at 714.

²⁰⁷ Robson, *supra* note 96, at 191 (noting the need “to include the male as an equal partner, but at the same time understand the male’s need to protect his identity as supporter”).

²⁰⁸ See Korenromp et al., *supra* note 68, at 259 (“Low-educated patients are more vulnerable and consequently need more support”); see also *supra* notes 57–58 and accompanying text.

CONCLUSION

Pregnancy termination due to a fetal abnormality is a unique category of abortion resulting in a significant risk of grief, depression, and post-traumatic stress for women and their partners, as well as potential harm to living children. Women who learn of a fetal abnormality are forced to reconsider having an abortion after already having declined to terminate. The information they receive as they decide whether to bring a genetically anomalous fetus to term is incomplete, informed by their perceived status and ability to care for a child having a potential disability, and at times directive in encouraging termination. Eleven states and Congress have attempted to address this information deficit legislatively, but these efforts suffer from drafting oversights and limitations in scale and scope that render them largely ineffective. Due to the recent expansion of insurance coverage for prenatal genetic analysis under the Affordable Care Act and the arrival of noninvasive methods of prenatal genetic testing, the number of women who learn of fetal abnormalities during pregnancy will rise sharply in coming years. This will broaden the pool of women and their families forced to grapple with the ethical challenges of considering a genetic termination and will expose a far larger population to potentially life-altering psychological consequences. The proposals set forth in this Article aim to provide those facing this challenge with adequate information about the range of pregnancy outcomes and access to the support services available to them whether or not they choose to terminate. In this regard it is but a modest proposal, though addressed to a crucial and growing need.

