ONE SMALL STEP FOR GENETICS, ONE GIANT LEAP FOR GENOCIDE?

Judith Daar*

In a thoroughly comprehensive and accessible manner, displaying her characteristically elegant and persuasive prose, Professor Jaime King makes the case for a modest but well-developed private regulatory scheme to address the emerging use of non-invasive prenatal genetic testing. In And Genetic Testing For All...The Coming Revolution in Non-Invasive Prenatal Genetic Testing, King describes recent advances in prenatal diagnosis using cell-free fetal DNA (“cffDNA”) material found in a woman’s blood at the earliest stages of pregnancy.1 By studying these fragments of fetal DNA, scientists can detect a wide range of genetic and chromosomal conditions at a point in the pregnancy when medical, rather than surgical, abortion is a maternal option.2 Access to this much information, this soon in the pregnancy, this easily, King labels as “revolutionary,”3 boldly positing, “[e]verything is about to change.”4 Knowing a child will be born with a genetic anomaly, even one considered benign or treatable, she worries, will “create significant pressure on women . . . to . . . terminate affected fetuses.”5 To combat this reflexive reaction, King suggests a series of clinical solutions, including a two-step informed consent process that disaggregates the...
imparting of information about the genetic test, from the decision to consent to the simple procedure.\textsuperscript{6}

King’s approach is to look holistically at the legal, ethical and medical implications of easy and early genetic testing, and to then shape policies that promote what she considers a responsible use of the emerging technology.\textsuperscript{7}

Looking broadly at King’s analysis, I understand her to make four distinct, inter-related assertions:

1) Non-invasive prenatal genetic diagnosis ("NIPD") will be transformative because it will greatly expand the population who will access prenatal genetic testing, as well as the nature and amount of information available.\textsuperscript{8}

2) Current modes of delivery and incorporation of genetic information are highly problematic and ill-equipped to meet the challenges of NIPD.\textsuperscript{9}

3) Test results that indicate the fetus is affected by a genetic anomaly will most likely result in pregnancy termination.\textsuperscript{10}

4) Women will experience increasing pressure to test and selectively abort affected fetuses. Therefore, significant barriers should be put in place to counteract this pressure.\textsuperscript{11}

This commentary will address each of these assertions against the scientific backdrop that King incorporates in her article. That is, while she acknowledges at the outset that scientists are still at the “proof-of-principle” stage in using cfDNA to map the fetal genome,\textsuperscript{12} her analysis assumes that this form of non-invasive prenatal diagnosis will rival or exceed existing technologies in its reveal of the unborn child’s genetic make-up.\textsuperscript{13} Assuming a simple blood test less than two months into a pregnancy can accurately detect any and all fetal genetic anomalies, will this advancement and our response thereto “create[... the opportunity for collective individual parental decision-making to change the constitution of society ” as King predicts?\textsuperscript{14} I think not. To my mind, cfDNA testing will find its place on the ever-widening spectrum of technologies that provide greater and earlier

\begin{itemize}
\item \textsuperscript{6} \textit{Id.} at 602–03.
\item \textsuperscript{7} \textit{Id.}
\item \textsuperscript{8} \textit{Id.} at 612.
\item \textsuperscript{9} \textit{Id.} at 642.
\item \textsuperscript{10} \textit{Id.} at 627–31.
\item \textsuperscript{11} \textit{Id.} at 655–56.
\item \textsuperscript{12} \textit{Id.} at 610.
\item \textsuperscript{13} \textit{Id.} at 616–19.
\item \textsuperscript{14} \textit{Id.} at 655.
\end{itemize}
genetic information about our offspring, but will not fundamentally change
the trajectory of modern reproduction. As the history of reproductive
technologies reveals, the introduction of each new modality incites a period
of moral panic that gradually resolves into acceptance and integration into
clinical practice.\textsuperscript{15} NIPD through cfDNA may open the door to vast genetic
information, but it will not change the course of human reproduction.

While NIPD may not be utterly transformative, it will likely be
integrated into routine obstetric practice and thus deserves our reflections at
this early stage. My goal herein is to create a context to view this emerging
technology and to highlight the possible harms it poses to familial privacy
and reproductive freedom. In Part I, I urge that NIPD’s impact be studied in
the context of all prenatal testing that women now employ, not just those that
investigate the fetal genome. Comparing the possible utilization of this
simple new blood test to highly specialized and invasive genetic testing
inflates the impact that NIPD will have on reproductive decision-making.
Part II highlights disclosure dilemmas that continue to swirl around genetic
testing. We are far from the ideal where informed physicians adequately
inform patients about the meaning and consequences of genetic test results.
NIPD will only add complexity because of its ability to detect heritable
anomalies. Part III responds to King’s and others’ suggestions that genetic
testing and test results be regulated to avert discriminatory practices
embodied in women’s collective choice to abort affected fetuses. Limiting
access to genetic testing shifts authority over reproductive decision-making
from the patient to the state, a transition I urge we reject.

I. DEFINING THE NUMERATOR: WILL NIPD CHANGE THE PERCENTAGE OF
PREGNANT WOMEN WHO ACCESS PREGNATAL GENETIC INFORMATION?

Two percent. This is the total percentage of U.S. pregnancies on which
prenatal genetic testing is performed annually.\textsuperscript{16} King reproduces and relies
on this exceedingly low number from data investigating the use of two types
of invasive prenatal genetic testing—chorionic villus sampling (“CVS”) and
amniocentesis.\textsuperscript{17} We could bump up the numbers slightly by adding

\textsuperscript{15} See, e.g., Elizabeth S. Scott, \textit{Surrogacy and the Politics of Commodification}, 79
that accompanied introduction of commercial surrogacy, and its dissipation as the predicted
harms were not realized).

\textsuperscript{16} See Henry T. Greely, \textit{Get Ready for the Flood of Fetal Gene Screening}, 469

\textsuperscript{17} King, \textit{supra} note 1, at 616 n.70 (citing Greely, \textit{supra} note 16, at 289).
preimplantation genetic diagnosis (“PGD”), now used in about 5,000 IVF cycles annually.\textsuperscript{18} Each of these techniques involves a needle biopsy, either of the placenta or the early embryo, posing a risk of miscarriage or embryonic demise. In contrast, NIPD poses no such risk to the embryo or fetus, thus King reasonably concludes that the availability of testing via cffDNA will dramatically increase the percentage of pregnant women who avail themselves of genetic testing because they will be spared the “expense, discomfort, and risks to mother and fetus” that current methods pose.\textsuperscript{19} Moreover, this broad base of genetic data, gained early in the pregnancy, may “expand the reasons for which [women] selectively abort.”\textsuperscript{20}

I see two flaws with this analysis. First, King relies on inclusion criteria that are far too limited for the sweeping conclusion she draws. To measure the impact NIPD might have, our baseline for comparison should be the percentage of women who currently seek any type of prenatal screening. To ignore that a large majority of U.S. women already investigate the health status of their unborn children works a gross overstatement of the contribution NIPD might make to reproductive conduct and decision-making. Second, I think King and others before her overemphasize the role that genetics play in reproductive decision-making by underestimating the impact of nongenetic findings. While the diagnosis of a genetic anomaly may prompt a woman to contemplate her reproductive options, including abortion, so too would the discovery of a somatic lethality. Parental focus is not so much on the etiology of a health-affecting condition, but rather on what that disease will mean for the life of the future child.

\textbf{A. Inclusion Criteria for Measuring Prenatal Testing}

King builds the case that prenatal genetic testing through cffDNA will far surpass existing testing levels for three reasons: 1) the simple blood test is non-invasive to the uterus and thus poses no risk to the developing fetus; 2) the results can be available as early as seven weeks gestation when medical abortion remains an option; and, 3) the test will be far less expensive, and thus more accessible, than current forms of prenatal genetic testing.\textsuperscript{21} Each of
these factors, King argues, coalesce to dramatically increase a woman’s motivation and ability to learn her child’s genetic fate when the “information . . . is more actionable.” But studies confirm that women are already highly motivated to learn about the health of their fetus, and do so in large numbers. In fact, the demand for prenatal information dates back nearly a half century.

The armamentarium of prenatal tests first took shape in the late 1950s and early 1960s with the introduction of ultrasound into obstetric practice. Prenatal screening advanced in the 1970s, as physicians began to routinely offer their pregnant patients maternal serum screening via a simple blood test. The results were used to measure biochemical markers associated with several conditions in the fetus, including neural tube impairments such as spina bifida and anencephaly, and Down syndrome. Today’s pregnant woman can add amniocentesis and CVS to her “to do” list, assuming she did not already survey her child’s genome via PGD. While these latter invasive and risk-carrying tests are scarcely employed in the general population, ultrasound and maternal serum screening are routine components of prenatal care. According to the Centers for Disease Control (“CDC”), two-thirds of U.S. women have at least one ultrasound during the course of their pregnancy.

22. Id. at 602.
24. Id. at 79–81.
25. Id. at 81–82.
26. Id. at 79–81.
27. See ROTHSCHILD, supra note 23, at 79–84. The use of maternal serum markers to assess fetal health, commonly referred to as a “triple screen,” looks for three types of biochemical markers in a pregnant woman’s blood during the second trimester of pregnancy. Id. at 81. Elevated and low levels of certain markers can be associated with certain neural tube and genetic defects, and often prompt women to follow up an abnormal finding with ultrasound or amniocentesis. See PREGNATAL TESTING AND DISABILITY RIGHTS 45–49 (Erik Parens & Adreinne Asch eds., 2000) [hereinafter PARENS & ASCH].
28. See JOYCE A. MARTIN ET AL., CENTERS FOR DISEASE CONTROL & PREVENTION, 54 NATIONAL VITAL STATISTICS REPORTS, BIRTH: FINAL DATA FOR 2003 14 (Sept. 8, 2005). The rate of amniocentesis for 2003 was 1.7%, a decline from the 3.2% reported in 1989, due in large measure to the increased use of noninvasive screening tests such as ultrasound and measurement of maternal serum markers. Id.
29. ROTHSCHILD, supra note 23, at 79–82.
pregnancy.\textsuperscript{30} Data about the use of maternal serum screening suggests similarly robust utilization.\textsuperscript{31}

To be fair, ultrasound and maternal serum screening are not per se prenatal genetic tests, in that neither can reveal the genome of the subject fetus. But both can assist in the diagnosis of a genetic disorder by uncovering structural or biochemical markers associated with specific genetic diseases. For example, a first trimester ultrasound performed between the 11th and 13th week of pregnancy can detect extra fluid behind the fetal neck, possibly indicating a chromosomal disorder. First trimester maternal serum screening that shows a high or low level of a pregnancy protein can likewise mean a genetic fetal anomaly.\textsuperscript{32} These interventions are considered screening tests, and require targeted diagnostic tests to confirm or rule out the suspected disorder. The use of NIPD, at least in the earliest stages, would likely be considered a screening modality, with more reliable (and invasive) diagnostic testing recommended should a concerning marker appear in the results.\textsuperscript{33} Clinically speaking, until NIPD can accurately diagnose genetic anomalies, it will find its place among existing screening mechanisms already in wide use nationwide.

Expanding the inclusion criteria for measuring the use of prenatal testing that yields genetic information to include all current modalities reconfigures one’s perspective on the potential impact of NIPD. Instead of starting at a 2% baseline (looking only at amniocentesis and CVS), we should begin our comparison with the near 70% of U.S. women who now seek prenatal screening through ultrasound and serum screening.\textsuperscript{34} From this vantage point, NIPD is unlikely to drastically change the uptake of prenatal reconnaissance.

B. Overemphasizing the Role of Genetics in Prenatal Diagnosis

A growing worry about the burgeoning field of genetics is that the more we learn, the less we tolerate. That is, as we discover the genetic basis for all

\textsuperscript{30} Martin et al., supra note 28, at 13. According to the CDC, in 2003 (the most recent year for which statistics are available), 67% of women who had live births in the U.S. received an ultrasound, a steady increase from 47.6% in 1989. Id.

\textsuperscript{31} Id. at 13–14. King reports that in at least one state that requires pregnant women to be offered prenatal genetic screening via maternal serum markers, 70% accept. King, supra note 1, at 616.


\textsuperscript{33} See Greely, supra note 16, at 290–91.

\textsuperscript{34} See supra text and accompanying notes 29–31.
human behaviors, traits, and illnesses, we will employ this information at the earliest stages of life to screen out embryos that will or might display any “imperfections.” In her book, The Dream of the Perfect Child, Joan Rothschild argues that all forms of prenatal diagnosis, from ultrasound to amniocentesis to chorionic villus sampling to PGD, create what she terms “a discourse of the perfect child.”\(^{35}\) This discourse demands that parents reject, via abortion or embryo discard, anything less than a perfectly healthy child. Professor Rothschild laments the increasingly routine use of prenatal testing, which fuels the expectation on the part of medical personnel and society at large that the purpose of testing is to eliminate those with anomalies from the population.\(^{36}\) “The discourse that emerges in reproductive medicine characterizes the birth of a child with ‘defects’ as a tragedy, to be avoided by every means that science and technology can muster.”\(^{37}\) Others in the disability rights community echo this concern, and also express a “fear of elimination” as parents select against more and milder genetic anomalies.\(^ {38}\)

King acknowledges these concerns and appears in accord that it is the genetic nature of prenatal information that causes it to be so socially explosive.\(^ {39}\) Knowing that a child will be born with a gene-linked disease, or a chromosomal abnormality, or be predisposed to an adult-onset genetic disorder are at the heart of King’s analysis that parents will take action upon delivery of this information because it is perceived as definitive and directive. The parental decision pattern that is assumed to follow is: if an anomaly is genetic, it is part of every cell of the child’s body and thus only eliminated by terminating the pregnancy. King’s concern is that the onslaught of genetic information available through cfDNA testing will only accentuate this pattern.\(^ {40}\)

I don’t refute that parents react strongly, even harshly and rashly upon learning their fetus expresses a genetic anomaly linked to a childhood or adult-onset disease. What I emphasize, again, is that measuring the impact of NIPD on reproductive decision-making requires a broader-based view of existing practices. How many parents who learn their child will be afflicted...
with a nongenetic but disabling disorder proceed with their pregnancy? If a woman is told after a first trimester ultrasound that her fetus suffers from anencephaly, a serious developmental defect of the central nervous system in which the brain and cranial vault are grossly malformed, would her decision pattern be impacted by the etiology of this devastating diagnosis? Not as to this pregnancy. While the discovery of genetically-based prenatal information may influence reproductive decision-making in the future, it is the condition itself that drives parental action in any given pregnancy. The difference between knowing that a child will suffer because of a genetic or congenital illness is of no moment; all that matters is how that disease will impact the child’s life.

In the world of prenatal genetic testing, much is made of the discovery of genes that predispose the future child to certain or likely adult-onset diseases. Today we can know whether a three-day old embryo will develop a range of diseases as an adult, including Alzheimer disease, Huntington’s disease, breast cancer, and high cholesterol. The worry is that discovery of these predispositional genes will provoke parents to discard or abort these lives, not taking into account the possible medical breakthroughs that could occur in the intervening fifty or so years. Again, I question whether such patterns are limited to adult-affecting genetic disorders. If parents are told upon ultrasound that their child has a congenital heart condition that could pose health problems later in life, they will undergo the same risk/benefit calculus they would if the condition were discovered via a genetic test at the same point in the pregnancy. While knowing the information sooner in the pregnancy could impact parental choice, knowing the cause of the problem will not. I merely argue that fixating on the genetic basis, rather than the burden of any anomalous finding, overstates the role that genes play in parental decision-making.

41. According to Medscape Online, the cause of anencephaly is thought to be both genetic and environmental. Anencephaly, like other forms of NTDs [neural tube diseases], generally follow a multifactorial pattern of transmission, with interaction of multiple genes as well as environmental factors, although neither the genes nor the environmental factors are well characterized. In some cases, anencephaly may be caused by a chromosome abnormality, or it may be part of a more complex process involving single-gene defects or disruption of the amniotic membrane.

42. See Dena Towner & Roberta Springer Loewy, Ethics of Preimplantation Diagnosis for a Woman Destined to Develop Early-Onset Alzheimer Disease, 287 J. AM. MED. ASS’N. 1038, 1038 (2002).
II. GENETICS FOR DUMMIES: DELIVERING, EXPLAINING AND PROTECTING GENETIC INFORMATION

Advances in genetic technology, including the development of cfDNA testing, clearly enhance our ability to glean genetic information from a myriad of sources, but the necessary companion skills to understand and communicate the clinical and societal meaning of that information remain woefully underdeveloped. King points out that the two key stakeholders in the coming NIPD revolution—providers and patients—seem ill-prepared to effectively utilize the broad-based genetic revelation that early fetal testing will provide.\textsuperscript{43} On the provider side, if NIPD is offered as part of routine obstetric care, King laments that “few obstetricians have sufficient training in genetics or available time” to fully inform “patients about the risks and benefits of engaging in prenatal genetic testing.”\textsuperscript{44} Geneticists, who are specially trained to convey this information to patients, are too few in number to handle the onslaught of pregnant women likely to take up the new technology. On the patient side, pregnant women struggle to understand the clinical meaning of genetic test results, and often experience negative social and psychological sequella as a result of undergoing prenatal genetic testing.

I agree with King’s concerns and want to build on the impact NIPD could have on patients. As a premise, I assert that many, if not most people fundamentally misunderstand genetic information,\textsuperscript{45} and for good reason. The subtleties and unknowns in the field today outweigh the specifics and certainties. Any given test result may require a fairly sophisticated understanding of the concept of penetrance\textsuperscript{46}—the likelihood that a disease will manifest in the future child, as well as phenotypic expression\textsuperscript{47}—the
severity of symptoms a child will experience. While many genetic disorders can be detected prenatally, knowing that a child has a genetic anomaly will not necessarily tell the parents how the child will fare health-wise in the future. Down syndrome is a good example of this uncertainty. According to the National Down Syndrome Congress, “[t]here is wide variation in mental abilities, behavior and physical development in individuals with Down syndrome. Each individual has his/her own unique personality, capabilities and talents.” The mysteries deepen when a test reveals that a child may express the disorder, or will express the disorder much later in life.

Scholars in the disability rights community have spoken about the effect that prenatal revelation of a genetic disorder has on expectant parents. As explained by Professors Adrienne Asch and Erik Parens, when a child has a disability, “a single trait stands in for the whole, the trait obliterates the whole” with “no need to find out about the rest.” In the context of disabilities and prenatal testing, detection of a genetic disability often leads to selective abortion because the parents view the fetus only in terms of the disability, paying no regard to the many other qualities of the potential child. The parent sees the prospective child only as the disability, and this single trait enables the parents to justify their action. The abortion is ridding society of the disability—not of a child who, despite or possibly because of the disability, could lead a productive and happy life. Asch and Parens further surmise that refusing to gestate or aborting a disabled child is a way of preserving and upholding parental notions about the role that reproduction will play in their lives. Certainly the wealth of information NIPD will provide could exacerbate the chain of events Asch, Parens and others bemoan.

detected through CVS and amniocentesis, but to date there is no clinical measure for the severity of symptoms associated with the disease. According to the National Institutes of Health, “Down syndrome symptoms vary from person to person and can range from mild to severe.” Down Syndrome, MEDLINE PLUS, http://www.nlm.nih.gov/medlineplus/ency/article/000997.htm (last visited Oct. 18, 2010).


49. See PARENS & ASCH, supra note 27, at 13.

50. Id. at 13. Professors Parens and Asch lament this parental view as “unfortunate, often misinformed” because they overestimate the negative aspects and underestimate the value and satisfaction of parenting a disabled child. Id. For a contrary view, see Janet Malek, Disability and the Duties of Potential Parents, 2 ST. LOUIS U. J. HEALTH L & POL’Y 119 (2008) (advocating “The Strong Claim” that parents are morally required to use reproductive technologies to reduce the likelihood of birthing children with serious disabilities).
A second observation about the impact NIPD could have on patients focuses on the issue of genetic privacy. A well-known feature of genetic information is that it is not self-limiting to a single individual. Knowing the make-up of one person’s genome creates inquiry notice that lineal or collateral relatives could have contributed to or acquired the same traits. King acknowledges this phenomenon in the context of Huntington’s disease, observing that prenatal testing may reveal that both the fetus and the parent have the genetic disorder—something the parent may have purposely avoided discovering. The reach of genetic suspicion can extend beyond the private two-party relationship between parent and future child to include grandparents, siblings and other collateral relatives.

If a genetic anomaly associated with a lethal adult-onset disease is detected, do physicians have a duty to disclose this finding to family members who may be at risk? How about a family member’s duty to disclose? Should one woman’s reproductive investigation oblige her to disclose heretofores unknown family “secrets” to her brothers and sisters? The law is only beginning to grapple with questions of disclosure, with at least a few courts finding physicians liable for failing to warn family members about the genetic nature of their relative’s disease. While no court has yet assessed liability against a prospective parent for failing to warn blood relatives of newly discovered genetic anomalies in the family line, such a case is not altogether unthinkable. The uptick in prenatal genetic testing will surely pose these and other disclosure conundrums for years to come.

III. IDENTIFYING THE HARMs IN EXPANDED Prenatal GENETIC TESTING: Allocating Autonomy BETWEEN PATIENT AND PROVIDER

The assertion of harm surrounding prenatal genetic testing tends to focus on the loss of fetal life, as well as the impact that selective abortion for genetic anomaly has on those living with the disorder at issue. Selective abortion, it is argued, shows disrespect for fetal life as well as discrimination against those living with disabilities by inferring that such a life is not worth

51. King, supra note 1, at 645.
living. While King raises this latter disability rights discourse, she does not seem to embrace either the concern about fetal demise or harm to disabled individuals as a basis for altogether disallowing NIPD. In fact, her aim is to suggest practical solutions that will ease the inevitable entry of the technology into routine obstetric practice. The harm she worries most about, I think, is the clash between our rights-based reproductive autonomy jurisprudence and the need for some regulation to promote responsible use of prenatal genetic testing. In the end, King suggests a (slight) shift in reproductive autonomy from patient to provider, buoyed by a regulatory system that limits access to the full range of genetic disclosure technologies. This power shift from patient to physician and state reflect a worrisome trend in the degradation of women’s reproductive rights.

A. Shifting Autonomy from Patient to Provider

King’s view of reproductive autonomy as defined by the current, though dissipating, right to seek pre-viability abortion is best captured by her entreaty, “[a]s a society, we will need to consider how to best balance an individual’s desire to access all scientifically available information with the interest of a state to protect fetuses from being destroyed for trivial reasons.” Language shapes perception. Here, the clear implication is that women are killing fetuses for reasons that lack validity, and therefore giving pregnant women access to prenatal genetic information will only increase this behavior. In the context of prenatal genetic testing, King worries that early and easy access to data on fetal health will create a “loop-back effect” by expressing “disapproval for and reduction in support of women with disabled children, which, in turn, may increase the pressure to test” and “terminate affected fetuses.” Empirically speaking, King is correct that the discovery of a genetic anomaly is highly associated with so-called therapeutic abortion. Longitudinal studies show that women who learn their fetuses are affected with a “severe” condition elect termination in nearly 90% of cases.

54. Id. at 650–52.
55. Id. at 657.
56. Id. at 654.
57. See Rothschild, supra note 23, at 117–18 (reporting 81% termination rate from 1992-4 when condition discovered via amniocentesis; 89% termination rate in 1994 when condition discovered via CVS).
The essential question posed is should the type and timing of NIPD results alter the autonomy women have to make decisions about their pregnancies? The moving target that is women’s reproductive liberty experienced a shift toward greater governmental control in 2007 when the U.S. Supreme Court upheld the Federal Partial Birth Abortion Act, restricting both “when” and “how” a woman can terminate her pregnancy.\(^{58}\) NIPD poses the “why” thread of the abortion calculus—should a woman’s reason for seeking an abortion impact her ability to access this medical procedure? While King acknowledges that currently the state “cannot regulate a woman’s ability to have an abortion for a specific reason,”\(^{59}\) she raises the intriguing possibility that in the absence of formal regulation prohibiting abortion for “trivial reasons,” physicians could act as the arbiters of prenatal choice.\(^{60}\) “[I]ndividual physicians may consider the social consequences in determining whether to offer certain tests in the prenatal context.”\(^{61}\) Using the example of gender selection, King offers, “some physicians may opt not to offer NIPD for non-medical sex selection, because they do not believe parents should terminate a fetus based on such information.”\(^{62}\) Professional autonomy, she argues, allows physicians to refuse “to offer certain tests based on personal beliefs or potential social consequences.”\(^{63}\)

I am no more comfortable allowing the state to suppress personal information about an individual (from the person) than I am imbuing a physician with that authority. Allowing providers to decide what information a woman should be able to access based on the physician’s personal beliefs mangles patient autonomy to the point of nonexistence. Moreover, in a system where physicians decide what information to provide to patients based on the doctors’ personal beliefs, there are no safeguards such judgments will be made in an unbiased and nondiscriminatory manner. Instances in which reproductive service providers have impermissibly discriminated against patients based on personal characteristics are well

---

58. Gonzales v. Carhart. 550 U.S. 124 (2007). In upholding the law as not posing a substantial obstacle in the path of a women seeking a late-term abortion, the Court reasoned, “the State may use its regulatory power to bar certain procedures and substitute others, all in furtherance of its legitimate interests in regulating the medical profession in order to promote respect for life, including life of the unborn.” Id. at 158.
59. King, supra note 1, at 657.
60. Id.
61. Id. at 638.
62. Id.
63. Id.
documented. Also, shifting decisional authority to physicians disrupts the long-standing doctrine of informed consent. The linchpin of informed consent is the free flow of material information from physician to patient. Vesting the physician with the ability to selectively withhold critical facts substantially diminishes the patient’s decision-making capacity.

An oft-offered example of physician autonomy in an era of reproductive technologies are the ART providers who refuse to offer PGD for nonmedical sex selection. These physicians are technically capable of discerning the sex of a preimplantation embryo, but refuse to do so if the parents’ motive is to select a particular sex for nonmedical reasons. To me, this practice is not analogous to refusing to offer certain noninvasive screening tests for fear that patients will opt to abort for the “wrong” reasons. In the PGD scenario, the testing and transfer (or nontransfer) of embryos are closely linked and invested in a single practitioner. If a physician objects, for personal reasons, to nonmedical sex selection, refusing to test the embryos for sex at the outset (and discloses such policies up front to prospective patients) the patient can seek this service from another provider. By necessity, a single provider must be willing to test and transfer because of the rapid transition from testing to transfer that PGD involves. If a physician did agree to test for sex, and then refused to transfer selected embryos, the patient’s care would be jeopardized by having to search out another provider within hours of receiving the test results.

In the NIPD scenario, often the provider who tests will not be the one to perform the abortion. Moreover, if the woman elects abortion, the procedure need not be performed within hours. Finally, laws in most every state permit a doctor to opt out of performing abortions for reasons of personal conscience. Because the clinical act of testing and the act of abortion are

---

64. See, e.g., N. Coast Women’s Care Med. Grp., Inc. v. San Diego Cnty. Super. Ct., 44 Cal. 4th 1145, 1161 (Cal. 2008) (finding physicians potentially liable under state anti-discrimination law for refusing to treat a patient because she was in a same-sex relationship).

65. See Susannah Baruch, David Kaufman, & Kathy Hudson, Genetic Testing of Embryos: Practices and Perspectives of US In Vitro Fertilization Clinics, 89 FERTILITY & STERILITY 1053 (2008). In 2008, researchers at the Genetics and Public Policy Center surveyed U.S. fertility clinics about their use of PGD for sex selection. Id. The survey found 42% of respondents offer PDG for nonmedical sex selection, with 47% of this group willing to provide the technique under all circumstances (for a first child, for example). Id. Forty-one percent of those providing PGD for sex selection will only provide the service for family balancing. Id.

substantially delinked in the NIPD context, giving doctors the authority to selectively withhold the means of discovering information vital to a woman’s choice inflates and favors a physician’s autonomy over that of the patient. It makes no moral, legal or clinical sense to diminish a woman’s ability to make a highly personal decision in the name of physician autonomy when sufficient measures are already in place to protect this professional realm.

B. Shifting Authority from Patient to State

The introduction of new reproductive technologies inevitably raises questions about the propriety of regulatory responses. Typically, the pattern of social response is to favor comprehensive and restrictive regulation at the outset, a clamoring that has historically been unmet by lawmakers. After some years of utilization, with only low levels of continuing suspicion, the technology makes it way into fairly standard practice. Such was the case with artificial insemination, introduced in the 1950s, and IVF, circa 1978.\(^\text{67}\) The emergence of genetic reproductive technologies via PGD and soon NIPD are following a similar pattern. Professor King has written previously advocating federal regulation of PGD, suggesting the creation of a new agency to oversee the use and access to this emerging reproductive technology.\(^\text{68}\) As for governmental regulation of NIPD, King promises to address the issue in depth at a later time in a forthcoming article, but hints that she is amenable to some governmental oversight to assure the test’s accuracy and the provider’s proficiency.\(^\text{69}\) I am certain King’s excellent work will be an important addition to the growing commentary and advocacy surrounding the regulation of new genetic technologies. Not surprisingly, scholarly opinion on the subject is across the board, with some joining King in favoring a

\[\text{68. See Jaime King, Predicting Probability: Regulating the future of Preimplantation Genetic Screening, 8 Yale J. Health Pol’y L. & Ethics 283, 289 (2008) [hereinafter Predicting Probability] (suggesting the federal government create an independent agency to monitor and regulate the use of PGD).}\]
\[\text{69. King, supra note 1, at 657 n.308.}\]
Commentary on the value and mechanisms for regulating genetic technologies explore both informal and formal regulatory possibilities. As for informal or self-regulation, at least one scholar suggests a leading role for professional societies such as the American Society for Reproductive Medicine. Through the collective clinical and relational experience of its members, ASRM and other professional groups could develop guidelines for those in the field. Such guidelines would spring from a wealth of firsthand experience, assuring their clinical accuracy and credibility among practitioners in the field. The downside to self-regulation, King has warned in the past, is the inherent conflict of interest that motivates practitioners to calibrate their conduct “just enough to prevent government regulation.”

In terms of enacted law, looking to King’s previous writings I would expect her to support a role for the federal government in the regulation of NIPD. In the case of PGD, King has urged a fairly substantial regulatory scheme to promote the general welfare:

In order to protect society, the government should seek a regulatory strategy that enables it to identify social risks as they arise both in attitude and in practice. This will entail promoting extensive public discourse and monitoring discriminatory practices. These goals could be accomplished through notice and comment proceedings and public hearings, monitoring the use of PGS for certain conditions, predicting future demand, and employing a diverse staff of experts to identify and raise pertinent issues. Each of these features will be especially important as the government determines whether and under what conditions parents can screen for moderate medical and non-medical conditions.

---


73. King, supra note 68, at 326.

74. Id. at 340–41.
At the very least, I anticipate King will look to the federal government to collect and disseminate data about clinical practices, and if the data suggests that collective NIPD use results in “discriminatory practices” she would urge a robust governmental response, including a bar on access to the technology for certain uses. I infer from King’s previous salute to federal authority over PGD that she would support restrictions on the availability and use of NIPD, if such use proved “discriminatory,” i.e., resulted in too many abortions compared to existing baselines. Those baselines could be, for example, the number of abortions performed today as a result of genetic anomalies detected through CVS and amniocentesis. If the data showed that more women were electing abortion after NIPD than after CVS and amnio combined, then this may be the kind of increased discrimination King would seek to stave off. The discrimination, I suppose, is against those individuals currently living with the condition that incited the abortion. Or perhaps the worry is discrimination against women who choose to carry on with pregnancies and child-rearing in the face of a known genetic disorder. The argument, I think, is that a society that condones widespread abortion of fetuses with genetic anomalies expresses disrespect and a lack of support for individuals and their families living with such genotypes.

Is curtailment of reproductive liberty an appropriate, or even effective response to discrimination against the disabled? While good arguments can be made that reducing the population that experiences disabilities could impact the amount of scientific and social resources society expends toward treatment, cures, and support, I don’t find this externality compelling enough to justify the discrimination it engenders against pregnant women. Systematically depriving women of the right to access screening technology for fear that their (re)actions will indirectly harm an unrelated subgroup is burdensome beyond any semblance of fairness. Even if we rearrange the equation and define the “discriminatory practices” as the actions taken vis-a-vis affected fetuses, the burden remains. If the generalized concern is that NIPD will produce too many test-related abortions, then those seeking a regulatory solution should instead tackle our current “don’t ask, don’t tell” abortion jurisprudence. If early abortion remains a woman’s choice, then limiting her ability to make that choice in a fully informed manner is a deprivation of rights.

Protecting reproductive freedom seems particularly important at a time when many federal and state lawmakers have made clear their desire to
dismantle a woman’s right to choose early abortion. Whether by proscribing certain types of abortion procedures, or requiring waiting periods and ultrasound screening before the procedure can be performed, or defunding private organizations that provide access to abortion, the assault on access to abortion is well underway. Adding regulations that limit access to NIPD, while not a direct restriction on abortion, is clearly intended to have the same effect. Formally suppressing information that could be material to a woman’s choice manifests institutional mistrust of her decision-making capacity, and gerrymanders clinical outcomes toward those favored by the state. Concerns that women will misunderstand the clinical significance of genetic test results can be addressed in ways that do not further reduce their reproductive rights. King joins this dialogue by offering some creative solutions to address the information gap, a dialogue she has enhanced with her work.

IV. CONCLUSION

Opening a door in an unknown place is frightening for all the horrors we imagine on the other side. The door to the world of genetic discovery is no less daunting for all the unknowns that emerging branch of science poses. It is understandable that some would warn of dire consequences, urging we anticipatorily protect ourselves against the dismantling of norms and routines by the onslaught of never-before seen practices. NIPD has raised this consciousness, leading to worries it will revolutionize reproduction on a population level by vastly increasing the number of abortions performed for genetic fetal anomaly. I urge we view NIPD against a backdrop of what we know, as opposed to what we don’t know. We know that we have ushered in numerous other advances in reproductive technologies without upsetting the fundamentals of human procreation. We know that we already take great clinical advantage of prenatal testing that provides a window into our children’s genetic health. We know that depriving patients of information vital to their medical decision-making is antithetical to the requirement for informed consent, and a deprivation of established rights when such decisions involve pregnancy and childbirth. While we don’t know exactly how NIPD will be integrated into our reproductive health care system, we are

better served trying to understand its usefulness rather than quash its potential to teach us more about our genetic selves.