

Scholar, Innovator, and Mentor

Rachel Rebouché

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SCHOLAR, INNOVATOR, AND MENTOR

RACHEL REBOUCHÉ, J.D., LL.M.*

I met Professor Karen Rothenberg in 2011 when we were both visiting faculty members at the Berman Institute of Bioethics at Johns Hopkins University. I was in my second year of full-time law teaching, and Karen was an academic whose work I deeply admired. Karen's scholarship on prenatal testing and the gender implications of clinical research (to name just two contributions) had transformed the field of health law.¹

I was impressed with Karen's immediate and generous mentorship. Within a week of meeting at the Berman Institute, we were discussing the trajectory of prenatal genetic screening and testing. At faculty meetings, I learned that, in addition to being a well-known and respected scholar, Karen also was an avid student of the most cutting-edge issues in genetics and the law. After one faculty gathering, she approached me to talk about a new technology: non-invasive prenatal genetic testing (NIPT).

NIPT is administered early in pregnancy and screens the fetus for certain genetic characteristics. In 2011, NIPT had recently entered clinical practice.² Pregnant women traditionally relied on blood tests and ultrasounds to screen fetuses for genetic or physical anomalies. Depending on the level of risk, patients might elect a second trimester screen, followed by testing fetal cells collected through amniocentesis or chorionic villus sampling.³ NIPT, however, collects cell-free fetal DNA from a sample of the pregnant woman's blood.⁴ The test is 99% accurate at only nine or ten weeks of gestation with research demonstrating

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* Associate Dean for Research and Professor of Law, Temple University Beasley School of Law.

1. See, e.g., Karen Rothenberg, *The Law's Response to Reproductive Genetic Testing: Questioning Assumptions about Choice, Causation, and Control*, 8 FETAL DIAGNOSIS & THERAPY 160 (1993); R. Alta Charo & Karen H. Rothenberg, "The Good Mother:" *The Limits of Reproductive Accountability and Genetic Choice*, in WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 105 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994); Karen H. Rothenberg, *Gender Matters: Implications for Clinical Research and Women's Health Care*, 32 HOUSTON L. REV. 1201 (1996).

2. Jade Bennett et al., *Non-invasive Prenatal Diagnosis for BRCA Mutations – A Qualitative Pilot Study of Health Professional's Views*, 25 J. GENETIC COUNSELING 198, 198 (2016).

3. Peter A. Benn & Audrey R. Chapman, *Ethical Challenges in Providing Non-Invasive Prenatal Diagnosis*, 22 CURRENT OP. OBSTETRICS & GYNECOLOGY 128, 128-29 (2010).

4. Rowan Jacobsen, *Designer Genes*, 42 MOTHER JONES, Sept.-Oct. 2017, at 3 (stating NIPT has "become popular so quickly...because it's less invasive than traditional pregnancy screening techniques").

high levels of accuracy as early as six or seven weeks of pregnancy.⁵ At present, NIPT can identify aneuploidies (an abnormal number chromosomes in a cell) and detect fetal sex; however, NIPT, with advances in gene sequencing, promises to reveal more prenatal information in the not-too-distant future.⁶

Around the time that Karen and I were discussing NIPT, Karen was invited to contribute an article to a symposium issue on health care law for the *Howard Law Journal*. She wanted to write about the intersection of NIPT and abortion restrictions. Knowing of my interest in both topics, Karen asked if I would be willing to co-author a piece with her.

Most junior faculty members, asked by a leader in their discipline to co-author an article, might expect to do most of the work and receive half the credit. But that is not Karen's approach. We met to talk through ideas, exchanged numerous drafts, and worked as a team. Karen values building relationships with other scholars, and she sets a high standard in her research and writing while providing invaluable support as a collaborator.

I learned a great deal about prenatal genetic testing in the course of co-authoring our law review article, *Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion*. We argued that current law and practice put genetic testing and abortion on a collision course; what pregnant women could learn about their pregnancies was expanding while, at the same time, post-testing options were contracting.⁷ We predicted that the termination of pregnancies for reason of fetal anomaly would become a focal point of public policy debates and court decisions.⁸

Since we wrote *Mixed Messages*, state legislatures have passed laws banning abortion on the ground of fetal anomalies (as well as on the grounds of fetal sex and race). Most of these statutes have been struck down by federal courts. For example, the U.S. District Court for the Southern District of Indiana enjoined a law that banned abortion "solely because the fetus has been diagnosed with, or has a potential diagnosis of, Down syndrome or any other disability."⁹ The court noted that an impetus for the Indiana law was NIPT:

5. Mary E. Norton et al., *Non-Invasive Prenatal Testing for Fetal Aneuploidy: Clinical Assessment and a Plea for Restraint*, 121 *OBSTETRICS & GYNECOLOGY* 847, 850 (2013).

6. HENRY GREELY, *THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION* 86 (2016) ("In the longer run, ...NIPT should be able to test for single gene mutations or even provide a whole genome sequence. By making use of information about the parents' DNA, NIPT has already been used in [an experiment] to infer a fetus's entire genome. This is currently too expensive and uncertain for clinical use, but that will change."). Zuzana Deans et al., *For Your Interest? The Ethical Acceptability of Using Non-Invasive Prenatal Testing to Test 'Purely for Information'*, 29 *BIOETHICS* 19, 20-21 (2015).

7. Rachel Rebouché & Karen Rothenberg, *Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion*, 55 *HOW. L.J.* 983, 986 (2012).

8. *Id.*

9. IND. CODE § 16-34-2-1.1(a)(1)(K); *Planned Parenthood of Ind. & Ky. v. Commissioner of Ind. St. Dep't of Health*, 265 F.Supp.3d 859 (S.D. Ind. 2016).

The State presents evidence that these provisions were passed in light of technological developments that allow the diagnosis or potential diagnosis of fetal disabilities to be made early in a pregnancy. In particular, cell-free fetal DNA testing is able to screen for several genetic abnormalities, including Down syndrome, as early as ten weeks into pregnancy.¹⁰

On appeal, the U.S. Court of Appeals for the Seventh Circuit rejected the state's argument that genetic screening will result in discrimination against fetuses with disabilities and held that the provision was an unconstitutional restriction on a woman's right to pre-viability abortion.¹¹ A similar law passed in North Dakota, prohibiting abortion because of "any physical disfigurement, scoliosis, dwarfism, Down syndrome, albinism, or any other type of physical or mental disability, abnormality, or disease."¹² That law was enjoined by the U.S. Court of Appeals for the Eighth Circuit also on the ground that it unconstitutionally restricted the right to pre-viability abortion.¹³

These court battles highlight a point Karen has made so eloquently throughout her scholarship on the larger dilemmas presented by prenatal testing. Too often, in the midst of litigating constitutional rights in the face of anti-abortion legislation, the lived realities of pregnant women are obscured. After prenatal testing, pregnant women must make difficult decisions about terminating wanted pregnancies. They face pressures to test but with increasingly limited options of how to act upon resulting information. Karen was one of the first scholars to understand what those pressures mean for the quality of prenatal care women receive as well as the consequences for persons (and their families) with disabilities.

I am delighted to be a part of this fitting and well-deserved tribute to Karen's generosity of spirit and broad-reaching intellect. When we finished our *Mixed Messages* article, Karen encouraged me to present it to the Berman Institute faculty and at a conference hosted by Case Western Reserve University

10. *Planned Parenthood of Ind. & Ky. v. Commissioner of Ind. St. Dep't of Health*, __ F.3d __ (7th Cir. 2018), 2018 WL 1870566 at 5.

11. *Id.* at 862 ("The State urges that . . . it has compelling interests in prohibiting discrimination of particular fetuses in light of technological advances in genetic screening. . . . We cannot reweigh a woman's privacy right against the State's interest. The Supreme Court has been clear: the State may inform a woman's decision before viability, but it cannot prohibit it."). The United States Supreme Court recently considered Indiana's law and decided that, without a split decision from the federal circuit courts, it would not rule on the constitutionality of reason-based bans on abortion. *Box v. Planned Parenthood of Ind. and Ky.*, 587 U.S. __ (2019), available at https://www.supremecourt.gov/opinions/18pdf/18-483_3d9g.pdf.

12. H.B. 1305, § 2(1)(b), 63d Leg. Assemb. (N.D. 2013).

13. *MKB Management Corp. v. Stenehjem*, 795 F.3d 768 (2015) (striking down the entire bill but not discussing the provision on fetal disability). See also LA. REV. STAT. ANN. 40:1061.1.2 (2016) (prohibition to terminate "solely because the unborn child has been diagnosed with either a genetic abnormality or a potential for a genetic abnormality"). A challenge to the Louisiana law was ultimately dismissed on the ground that the plaintiffs had no standing because all abortions were banned at 20 weeks. *June Med. Serv. v. Gee*, No. 16-00444-BAJ-RLB, 2017 BL 411675 (M.D. La. Nov. 15, 2017).

School of Law. And I have since authored a series of articles exploring other aspects of NIPT.¹⁴ My collaboration with Karen was not only professionally rewarding but also personally enriching. She provided significant guidance at an early and important stage in my career. She is, in short, a model of what legal academics should offer to their colleagues and students.

14. See, e.g., Rachel Rebouché, *Non-Invasive Testing, Non-Invasive Counseling*, 42 J.L. MED. & ETHICS 228 (2015); Rachel Rebouché, *Testing Sex*, 49 U. RICH. L. REV. 519 (2015); Rachel Rebouché, *Contracting Pregnancy*, 105 IOWA L. REV. __ (2020).