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# BRINGING A HOLISTIC PERSPECTIVE TO LAW, MEDICINE, AND THE HUMANITIES: A TRIBUTE TO KAREN ROTHENBERG

FRANK PASQUALE, J.D., MPhil.\*

As a beginning health law scholar in the mid-2000s, it was impossible not to hear of Karen Rothenberg's work. Everyone knew about her tireless work to build the University of Maryland Health Law & Policy program into one of the best in the U.S., as well as her extensive scholarly work in bioethics. When I came to Maryland's "Avian Flu: What Can We Do?" conference in 2006, I was thrilled to learn from one of her initiatives. And imagine how pleased I must have been to be hired by Maryland in 2013.

Karen proved to be an invaluable mentor for me during a pretty rough transition into the new job. I've always appreciated her friendship and extraordinary leadership. But for this tribute, I want to focus on her scholarship, and particularly her work in law and literature. This is not a fashionable focus, given the legal academy's current inclination to chase the cultural cachet of the hard sciences via what David Beer has called "the data gaze."<sup>1</sup> However, by bringing the direct personal perspectives of individuals to the center of conversations on the propriety of genetic medicine, Rothenberg has shown the enduring importance of the qualitative in fields all too prone to gloss over fundamental conflicts of values with ersatz quantification.

Over the past decade or so, Rothenberg's writing has taken a literary turn, first focusing on literary criticism and the *Drama of DNA* (the title of her book with Lynn Wein Bush), and then turning to the writing of plays themselves.<sup>2</sup> As she explained in the *Fordham Law Review* in 2010, "Drama is uniquely able to address salient issues and to manipulate the way they are perceived through characters with whom the audience identifies and sympathizes. In this way,

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1. DAVID BEER, *THE DATA GAZE: CAPITALISM, POWER AND PERCEPTION* (2018).
2. KAREN H. ROTHENBERG & LYNN WEIN BUSH, *THE DRAMA OF DNA: NARRATIVE GENOMICS* (2011).

theatre engages in a dialogue with public opinion and social policy.”<sup>3</sup> What’s particularly fascinating here is that Rothenberg is not arguing that literature will lead us to a “truth” about genetic engineering, or even to optimal policy in the area. Rather, she praises its status as more and less than truth and justice: less, in the sense that the arts can “manipulate” audiences (evoking Plato’s famous suspicion of poets); and more, in that the structured imaginative experience afforded by literature or performance cultivates a wisdom irreducible to logic, algorithms, or even propositions.

Rothenberg’s turn to literature recognizes that our plays and poems, stories and films, reveal patterns of power and meaning in the world by exploring the ramifications of critical relationships. They illuminate fundamental aspects of human experience. They can trace the elemental and superficial, epochal and fleeting, to the ideas and institutions that shape the most important aspects of our lived reality.

To assign such meaning to literature (and, even more scandalously, to suggest it has some import for our perception of not only social reality, but also of policy and law meant to shape that social reality), is to risk ostracism among worldly elites. As sociologist Richard H. Brown has helpfully typologized, modernity is typically presumed to have clearly distinguished the following realms:<sup>4</sup>

|                   |                       |
|-------------------|-----------------------|
| Science           | Art                   |
| truth             | beauty                |
| reality           | symbols               |
| things and events | feelings and meanings |
| “out-there”       | “in-here”             |
| objective         | subjective            |
| proof             | insight               |
| determinism       | freedom               |

Fortunately, Brown only sets up these oppositions in order to reconcile them—or, more precisely, to create room for both sides in an intersubjective zone of social reality between objectivity and subjectivity.<sup>5</sup> In *A Poetic for Sociology*,

3. Karen H. Rothenberg, *From Eugenics to the “New” Genetics: “The Play’s the Thing,”* 79 *FORDHAM L. REV.* 407 (2011).

4. RICHARD H. BROWN, *A POETIC FOR SOCIOLOGY: TOWARD A LOGIC OF DISCOVERY FOR THE HUMAN SCIENCES* 26 (1977).

5. I draw this terminology from JÜRGEN HABERMAS, *THEORY OF COMMUNICATIVE ACTION: VOL. 2: LIFEWORLD AND SYSTEM: A CRITIQUE OF FUNCTIONALIST REASON* (1985). The three realms of subjective, objective, and intersubjective map (if imperfectly) to understandings of beauty, truth, and justice.

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Brown weaves together strands of thought from “pragmatists, existential phenomenologists, and ordinary language philosophers to replace” strict distinctions between facts and values.<sup>6</sup> A phenomenological study of intent and context defeats reductionism.

Rothenberg engages such a phenomenological analysis, analyzing the first-person confrontations with mortality and heredity that genetic knowledge portends. There is a fundamental divide between the born and the made, but the more we learn about the inner workings of the DNA, the more we risk blurring that boundary, and treating our progeny like manufacturing projects. For example, consider her discussion of Jonathan Tolins’s powerful play *Twilight of the Golds*:

When the play was first produced in Washington, D.C., it was described as “chillingly prescient”. . . . The plot centers on the character of Suzanne who finds out, through fictional cutting edge technology performed in her husband Rob’s lab, that her fetus is very likely to be gay. But early on in the play, even before she gets tested, Tolins sets up the tension between David, Suzanne’s gay brother, who serves as the narrator, and her husband, Rob. David says, “Face it, Rob, this is eugenics. It’s blatant Nazi philosophy.” Rob replies, “Oh, here we go. Every time there is the slightest scientific advance, some knee-jerk liberal starts shouting about the Nazis. We’re just trying to make life better.”<sup>7</sup>

This juxtaposition of these critical lines of dialogue from the play dramatizes the power of medicine, the arrogance of some researchers, and the troubling implications of predictive knowledge. We usually think that the more we know, the better our condition will become. But as Rothenberg skillfully foreshadows, science can just as easily be turned to the most evil ends imaginable. It must be governed by law and morals, lest the powers it grants be misused against the most vulnerable in society.

The ethical implications of Tolins’ scenario are obvious: abortion based on presumed sexual orientation is morally repugnant. In her own plays with Lynn Bush, Rothenberg examines more subtle dilemmas, crafting characters who must wrestle with the implications of more constructive medical interventions and research. For example, in the 2011 play “It’s Not That Simple! Genomic Research & the Consent Process,” Rothenberg and Bush present this scenario:

As the play commences, we find Bobby, Amy, Sam, and Ellen Friedman in the Pediatric Genetic Clinic with Dr. Hardy. Bobby is a nineteen-year-old with

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6. BROWN, *supra* note 4, at 29.

7. Rothenberg, *supra* note 3, at 426–27. For a critical analysis of the science of sexual orientation prediction, see two works by Professor Edward Stein. EDWARD STEIN, *THE MISMEASURE OF DESIRE: THE SCIENCE, THEORY, AND ETHICS OF SEXUAL ORIENTATION* (1999); Edward Stein, *Choosing the Sexual Orientation of Children*, 12 *BIOETHICS* 1 (1998).

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an autosomal recessive genetic disorder. His degenerative symptoms manifested several years ago, and are of a similar nature to those beginning to affect his sister, Amy, age sixteen. Sam, their nine-year-old sibling, does not have the heritable condition. They reside with Ellen, their mom, who is an elementary school teacher. Their dad, Howie, lives in another town with his second wife and young son.<sup>8</sup>

Dr. Hardy wishes to enroll the family in a new study, but some are reluctant, as this dialogue shows:

MOM: Just glancing at this, why are there so many warnings in this consent form?

SAM: Mom. . .Did you hear me? Can I walk over and play at Danny's?

MOM: OK, go play. I'll take care of your consent.

BOBBY: No wonder they need seven pages to explain things. They think we should be happy the whole world doesn't see our medical information. Listen:

"Researchers who have access to genetic information will take measures to maintain the confidentiality of your genetic information."

But how much of a measure, a ton or a drop in the bucket?

These superficially simple reactions in fact lay bare deep problems in consent processes. As the young Bobby wants to know, when we are assured that our privacy is protected, can we really count on such promises? Later in the dialogue, Bobby's mother is trying to reassure him about the password protections on such data, but he is not buying it. "Computers get broken into all the time," he says.

Written years before massive health data breaches brought the security of information to the top of journalists' and policymakers' agenda, the play is prophetic about substantive issues raised by a surfeit of health data. Via its narrative style, it offers a wisely cautionary tale of the limits of consent-based health data governance regimes. Bobby's vernacular patois, riddled with the clichés of a layman, belies a deep wisdom about the unknowability of the future. Given our radical uncertainty about developments in law, its enforcement, genetic knowledge, and its usefulness in diagnosis and treatment, the balance of benefits and burdens here is impossible to calculate. It is not a problem to be solved, but a mystery about which we can only hope to grow wiser. Rothenberg's work helps us do so.

In his review of *The Drama of DNA*, Jules Odendahl-James extols the book's "performance-based pedagogical approach to genomic medicine for

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8. Lynn Bush & Karen Rothenberg, *It's Not That Simple! Genomic Research and the Informed Consent Process*, 14 GENETICS IN MED. ONLINE SUPP. (2012). (This play is also on the Oxford Website for the book *The Drama of DNA*.)

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anyone who engages its ‘drama:’ as a researcher, clinician, health care administrator, ethical and legal advisor, genetic counselor, patient, or caregiver.”<sup>9</sup> This approach is a cornerstone of the medical humanities, which help ensure that humane values of patience, tolerance, and kindness inform the practice of medicine. Persons are not mere Hobbesian “matter in motion,” to be fixed like a broken clock (or discarded if unable to be ‘repaired’). Rather, when we are sick, we need to be understood, and not simply analyzed; healed, and not simply cured. And we need to talk about these needs to articulate them, rather than consigning the governance of health care to neoliberal technocrats’ bloodless cost-benefit analyses and endlessly manipulable outcome measures.

As Odendahl explains, medical humanities includes the “use and analysis of representative cultural products (i.e., literature, visual art, plays, films, music, creative non-fiction, comics) to inspire conversations about the human dimensions of clinical medicine, scientific research, and the health care industry.”<sup>10</sup> Rothenberg has both analyzed and produced these “representative cultural products.” Via that *oeuvre*, she has accomplished a rare academic hat trick, writing with deep and enduring relevance in law, medicine, and the humanities. She leaves a great legacy here in Maryland, and well beyond.

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9. Jules Odendahl-James, *Review of Karen H. Rothenberg and Lynn Wein Bush*, 16 AM. J. BIOETHICS W17, W17 (2016) (reviewing KAREN H. ROTHENBERG & LYNN WEIN BUSH, *THE DRAMA OF DNA: NARRATIVE GENOMICS* (2011)).

10. *Id.*