Symposium: The Coming Generation in American Bioethics

Crossing Invisible Lines

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My path to bioethics was a long and uncharted one. My journey, through a rich and varied career and three postgraduate degrees, reflects the evolving narrative of both my own life and the field of bioethics. As bioethics began to emerge as a field in the 1970s, I came of age studying the art of the Renaissance, reading Jean-Paul Sartre, and watching Ingmar Bergman films. Human freedom and individual liberty dominated the life of my mind. My university allowed undergraduates to satisfy the science requirement of a humanities degree through coursework in public health. To my surprise, I was captivated by the emphasis on justice and population health and wrote my senior honors thesis on the relationship between the literary arts and the social sciences. After college I headed to law school, where I fell in love with constitutional law and the liberties enshrined within the Bill of Rights. My first employer after graduating from law school was the Office of the Minnesota Attorney General, and my first client was the Minnesota state hospital for the mentally ill and dangerous. As fate would have it, in the early 1980s this was the epicenter of the legal struggle between individual rights and the public good.

After five years, I applied for and received a competitive regional fellowship then known as the Bush Leadership Fellowship. I spent a year at the Harvard School of Public Health, graduating with a master's in public health. After graduation, my fascination with population health led to what might at first glance seem an anomalous choice for employment. I joined a law firm that represented some of the largest managed care companies in the country. These were the optimistic days of managed care. Employers were adopting a population-based approach to healthcare. Managed care was the front line of new and creative public policy in population health. Health law was beginning to emerge as a distinct specialty, as was the field of health policy. In the early 1990s, I attended one of the first conferences on ethics and healthcare policy hosted by the National Institutes of Health.

There is an old environmental law phrase that "ethics begins where the law ends." In the mid-1990s, legal and ethical guidance on how managed care organizations should allocate resources across their populations was nonexistent. Bioethics was just beginning to move from a primary concern with autonomy and beneficence to a focus on justice and health. Insurance mandates proliferated, ranging from stem cell transplants for late-stage breast cancer to cochlear implants for hearing loss. This was the era of capitation payment structures and prior authorization practices. New issues—with no legal answers—walked into my office every day. And, if there was law on the subject, it often led in a direction that appeared to be wholly unethical—as in mandated payment for highly experimental and expensive rescue therapy.

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By then employed as the vice president and associate general counsel for a large nonprofit managed care organization and lacking concrete legal or ethical guidance, I struggled with these decisions. We who worked in managed care did not even have the language to describe the hard choices that kept us awake at night; it was not unusual for my CEO to email us his late-night musings on the ethical dilemmas we faced. We decided we needed more than Sunday School guidance with these difficult decisions. We went in search of the best and the brightest to help us develop what we thought would be a simple set of principles. We found very gifted thinkers in Ezekiel Emanuel, M.D., Steve Pearson, M.D., Art Caplan, Ph.D., and Norman Bowie, Ph.D. They spent days with us. I traveled to Boston and the Harvard Community Health Plan to watch an intriguing and innovative organizational ethics practice called an ethics advisory group, chaired by Dr. James Sabin.

Later, with the help of Karen Gervais and the Minnesota Center for Health Care Ethics, I led a small team of thought leaders who drafted a set of ethical principles specific to an integrated delivery system that included hospitals, clinics, and a managed care organization. We trained employees to use the principles and established a system-wide forum for examining and reflecting on problems never before thought to have an ethical component. These included the closing of an unprofitable service line caring for a highly vulnerable population, the management of a complex pharmaceutical formulary, and the boundaries of nonprofit executive compensation. Our ethics process experienced both brilliant successes and stunning failures. Time passed and healthcare reform collapsed. The managed care backlash hit hard, and the center could not hold. The company reorganized, and the ethics work quietly disappeared.

As I approached the twentieth anniversary of my law school graduation, the complex regulatory schemes that had become health law no longer fascinated me. I found that I was more interested in the quandaries for which the law had no answer. Under what circumstances should a nonprofit organization use its limited resources to pay for expensive experimental therapy? How should a healthcare system decide to reduce the number of medical device vendors in order to take advantage of volume purchasing discounts? Because "what's budgeted is what gets done," how can ethics be integrated into a capital budgeting process? After twenty years as a corporate lawyer, I was very comfortable in the boardroom. Although interested in traditional bioethics issues, my true passion was in the intersection between ethics and health policy and the underdeveloped field of organizational ethics. It seemed clear that the power and ability to fundamentally change healthcare would increasingly reside at the organizational and policy levels. Improving access, reducing medical error, and bending the cost curve would require organizational vision, prioritization, and funding. What could ethics bring to the table?

After two decades, for me the law was like breathing; it was my native tongue and my personal orientation to the world of healthcare. Although I was deeply interested in the field of ethics, it remained something of a foreign language to me. I decided to pursue a master's in bioethics at Loyola University Chicago. I graduated in 2009 with a master's in bioethics and health policy, and by then my fluency was much improved. But, for me, bioethics is not yet like breathing. Like many practicing lawyers, I am a pragmatist at heart.

Bioethics has comparatively little experience on the business side of healthcare and struggles to demonstrate a clear value proposition for its work beyond the bedside. Ask the CEO of a typical healthcare system why a lawyer should have a place in the boardroom and the answer is immediate: healthcare is one of the most highly regulated businesses in the world. Ask why an ethicist should have a place in the boardroom and the same CEO is likely to pause, even though healthcare is one of the most ethically complex endeavors known to humankind. One of my aspirations is to be welcomed in the boardroom, not for my legal skills but for the valuable perspective I bring as an ethicist. When that value proposition is clear even to the skeptics in the boardroom, the future of *practicing* bioethics will be much more exciting.

As a lawyer and a student of the humanities, I wonder why bioethics becomes conservative when it comes to engaging in cross-talk with disciplines outside its self-proclaimed big tent, especially the disciplines of business and healthcare administration. In the twenty-first century, true interdisciplinarity requires familiarity with all the fields supporting the enterprise of healthcare. Similarly, bioethics often seems uncomfortable with the most interdisciplinary group of all—the body politic. Our legal system entrusts citizens with difficult and morally problematic issues, including punitive damages and the death penalty. The Presidential Commission for the Study of Bioethical Issues recently identified democratic deliberation as one of the five ethical principles relevant to emerging technologies. Yet the wider field of bioethics often seems suspicious of our citizenry and continues to debate the value of citizen expertise and participation, even with respect to issues like pandemic planning. Legal education places lawyers comfortably in the public square. I hope one of my contributions to bioethics will be to assist in keeping the moral space open in the public square of deliberative democracy.

Friends and family gently chide me about the multiple initials following my name—J.D., M.P.H., M.A. ''So what *are* you?'' they ask. ''Are you still a lawyer? Does the last degree win?'' Because bioethics does not credential its practitioners, it is up to me to declare when and/or whether I am a bioethicist. I know when I became a lawyer. It was not when I passed the bar exam or took the oath. It was many years later, sitting across the table from opposing counsel after 10 long months of negotiation. We had just finalized a complex contract under which both parties would flourish for many years. As everyone collectively exhaled, I knew I had crossed an invisible line from the world of becoming to a state of being. Although I am newly appointed to the faculty of a renowned center for bioethics, I have not yet crossed a similar line in bioethics. I am still becoming and suspect that, as happened during my journey as a lawyer, I will quietly and inwardly know when I cross that invisible line.