

In this series of essays, *The Road Less Traveled*, noted bioethicists share their stories and the personal experiences that prompted them to pursue the field. These memoirs are less professional chronologies and more descriptions of the seminal touchstone events and turning points that led—often unexpectedly—to their career path.

## *It Is Hard to Get There without a Guide*

### *How I Came to a Career in Bioethics*

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Students often ask me how I got into the field of bioethics. Sometimes the question is motivated by pure curiosity. Sometimes the motivation is to figure out how they might chart a career path into the field for themselves. If it is the latter, I have to remind them that when I decided to “do” bioethics by accepting a preceptorship position (whatever that was) in 1975 at the Columbia University’s College of Physicians and Surgeons, there was no field of bioethics as they think of it today. In fact, when I decided to accept the offer, there was no field of bioethics as anyone thought of it then. The preceptorship was to work on “ethics and values in healthcare,” a mission that I accepted with enthusiasm but about which I had barely a clue as to what was intended. It was the topics and the people, not expertise, that were shaping the early development of the field when I got interested in it.

More about what led to my taking a leap into the unknown later. For the simply curious, non-career-motivated inquirer, my interest in bioethics began in 1957 when I was seven years old. It started at the Children’s Service of the Massachusetts General Hospital.

I remember very clearly the moment when my parents first suspected I had polio. I was in their bedroom, on a Sunday morning, just goofing around with them and my sister, when my mother looked closely at me as I was rolling around on the floor and asked if I could lift my legs any higher than I had been doing. I could not. I had not really noticed any change. My parents did. They were well aware that one of the last pre-Salk vaccine polio outbreaks was sweeping through the Boston area. A few days later, after a truly horrible spinal tap and a bunch of physical exams, I was in a room at the Massachusetts General Hospital (MGH). This was the polio ward where I would stay for months, until, for a reason no one understood then or now, the poliovirus was beaten back by my body’s immune system.

I remember that when I first got admitted, the strength quickly left my legs and my neck. And I remember precisely when it returned.

The nurse had my daily hot bath ready to go. One of the treatments that I had gotten used to was heat therapy. Hot baths, heat packs, hot towels—heat was the key weapon the doctors and nurses deployed against the poliovirus that had left the muscles in my neck and legs paralyzed.

I did not know it, but an Australian nurse—Sister Kenny—had pioneered the therapeutic regimen I was getting. She had built a polio treatment program fifteen years earlier at the University of Minnesota, where I would wind up teaching many decades later. Sister Kenny saw her first case of polio in 1911. She thought, incorrectly, that polio patients' limbs were stiff, not permanently paralyzed. She also was unaware of the accepted medical treatment—using braces to keep limbs rigid. She thought it best to use hot packs and encourage gentle movement. Her treatment helped, but only in those few cases like mine that involved only temporary paralysis.

On this winter day in 1957 I was about to move from the sick group to the getting-better group. The nurse put me in the tub. She turned away. I thought about running. My legs responded. I jumped out of the tub, and for a reason that only a cooped-up seven-year-old would fully understand, took off out of the bathroom and ran down the hall. I might have run right out the door of the hospital, were it not for the fact that I was completely naked and dripping wet, and it was snowing outside. The polio was subsiding. I was about to get more acquainted with the work of Sister Kenny, because she also helped found the field of rehabilitation medicine, and I still had a lot more physical therapy ahead of me.

While I was in the polio ward in the hospital, there were plenty of injustices occurring. I remember being angry that my parents could not stay over or even visit for very long. And I remember being puzzled about why it was that the doctors would not tell us the truth about the kids who died. Death was never acknowledged, even when someone died during the night on the same floor as one or more fellow patients. At the age of seven I was sure that this was not the right way to deal with patients like me.

I went back for rehab at the MGH for a few more years. I did not like the long ride to the hospital from my home in Framingham, which, in those pre-Mass Turnpike days, took forever. I was not angry about this aspect of my care, but I did realize that rehab was much more about motivation than about medicine, which raised other interesting ethical questions.

My experience with polio is, I am sure, one of the reasons I do bioethics today.

I went on to high school at Framingham North. I had no interest in ethics, nor, despite having some great teachers and good friends with whom I still keep in touch, do I recall anything that occurred that would form the basis of any later bioethical interest. College was a different story.

When I went off to college at Brandeis University, I went as a premed. And I slogged along and took my required courses. However, Brandeis forced me to take some humanities courses, and as a result I became interested in both Chinese history and philosophy. The advanced courses in Chinese history met at 8 AM. Philosophy seminars met at 4. I took the philosophy route. I became very interested in this subject, which up until then I had no idea even existed, and wound up being a philosophy major.

I also was caught up, as every Brandeis student was in the late sixties and early seventies, in the social upheaval over the Vietnam War, civil rights, the use of marijuana and heavier-duty drugs (I inhaled but not very often), and the emergence of feminism. The last issue played out a bit differently at Brandeis, in that women were in active leadership positions and were not shy about speaking up around men. At one point on campus with me were Abbie Hoffman, Herbert Marcuse, Philip Rieff, Karl Popper, and Alisdair MacIntyre. Three students were eventually listed on the FBI's Ten Most Wanted List: Angela Davis, Susan Saxe, and Katherine Power. My interest in ethics was absolutely triggered by the swirl of controversies, strikes, demonstrations, and violent, rebellious acts that took place during this time.

I decided that I would not go to medical school or law school but would instead set out to study philosophy and then make a decision about which of the two to pursue. My mother has, at age 90, yet to regain her equilibrium regarding this choice.

I went to Columbia (partly due to getting a fellowship) and was immediately taken with the issues involved in the philosophy of science. I was privileged to take some courses with the distinguished philosopher of science Ernest Nagel, who supported my interest in studying evolutionary biology to identify issues in the philosophy of biology. I worked closely with the renowned biologist Walter Bock, a student of Harvard's Ernst Mayr, the giant of evolutionary biology, who introduced me to a host of issues that were hotly contested among those who sought to integrate Darwinism and genetic theory. Writing a thesis with Nagel, Sidney Morgenbesser, and Isaac Levi on why evolutionary theory was scientific whereas creationism was not led me both to believe that I would never encounter the intensity of insightful criticism I received from that trio (which has proven true) and directly into the path of the emerging field of sociobiology.

Sociobiologists were wrestling with one of the great conundrums of evolutionary theory—how could altruism and selflessness evolve, especially in creatures that did not reproduce? Their claims about genetic selfishness and reciprocal altruism were extended to humans, and that precipitated one hell of a public battle over the relevance of biology in explaining human behavior. My advisors did not care much about the public battle, but I did and found myself taking a break from my thesis to produce my first book, *The Sociobiology Debate*. I also found myself keenly interested in the interplay between ethics and science that sociobiology engendered.

Just about this time, in 1975, an ad appeared that said the medical school was looking for someone with a biology background to teach a short course in ethics to first-year students. I was perfect for the job, and because there was a paycheck involved, my wife urged me to apply, which I did. I got an interview with Bernard Schoenberg, M.D., a warm, engaging man who was a psychiatrist, a psychoanalyst, and the Dean of Academic Affairs. We hit it off. He became an advisor, mentor, and role model for me. He also encouraged me to take the job. That he quickly came to regret.

I taught about 100 medical students in a short, six-week elective course that was held two hours a week. I taught the course as a straight ethics course. By the end of the course, fewer than six students remained. My debut in the field of what later became known as bioethics had not gone well.

I went to see Dr. Schoenberg. I told him the course had been a disaster. He assured me he was well aware of that fact. I offered to return my pay. He dismissed that gesture with a wave of his hand and said, "You know science, you have done your premed requirements, and what you need to teach this course is some clinical experience, so I am going to admit you as a special student to this medical school." And he did.

I spent the next 18 months doing rotations in neurology, pediatrics, neonatology, nephrology, and my old stomping grounds, rehabilitation medicine, and taking various lecture courses. I peered into patients' eyeballs looking for papilledema, tried not to do anything with a needle or IV line that might harm anyone, amused my fellow students with my tale of rapid admission, and tried not to sound like an idiot when residents determined that I was way out of place and out of my league on the rotations. That said, I saw ethical issue after ethical issue—from decisions to let disabled infants die, to the rationing of scarce kidney dialysis machines, to efforts to create the first test-tube baby, and to the rapidity with which the label of "poorly motivated" was slapped onto a severely brain-injured patient whose home life and marriage was falling apart.

It was during this period that my interest and love of ethics and healthcare was born. The time I spent in the hospital and the particular places I went shaped everything I have done in my career.

I talked regularly to Schoenberg about what I saw and what I thought. He listened carefully, was always supportive and encouraging, and even urged me to try and build a team of students to work on ethical problems. The historian Alan Brandt, now Dean of Graduate Studies at Harvard; Betty Levin, a professor of sociology at Brooklyn College; Ann Dill, a medical sociologist at Brown; Kim Hopper at the Columbia School of Public Health; and Vanessa Merton of the Pace Law School were among those attracted to work with Schoenberg and with me.

I returned to teach the course I had so badly screwed up. This time, albeit with fewer students, it worked. A case-based approach proved to be the key to engaging the students.

A superb and tolerant mentor had gotten me into the field. Two more wonderful mentors were about to make sure I stayed.

I had seen an ad for a conference at Boston University (BU) on ethics and genetic testing. I sheepishly asked Dr. Schoenberg if I might be able to go. Without hesitation, he said yes, absolutely. As a result I clamored aboard the Eastern shuttle at LaGuardia (Eastern is long since dead, having been replaced by USAIR on this lucrative run) and headed to my old hometown.

There I briefly met a feisty young professor, George Annas, who would become a very good friend; John Fletcher from Virginia, who was doing pioneering work on the ethics of genetic counseling with Dorothy Wertz; the physician Robert Murray, who explained the challenges involved in large-scale sickle-cell screening programs; and many others. For me, however, the Eastern airlines shuttle proved to be of more sustained influence on my career path.

On the flight back I sat next to a curly-haired, short gentleman who, from the books and papers spilling out of his briefcase, had clearly also been at the BU conference. He looked at me and asked me what I thought of the meeting. I told Dan Callahan that I had enjoyed the talks, especially because I was interested in evolutionary biology and had not realized the way in which genetics was being put to practical use. I asked him what he thought, and he asked my impression of

his talk. I confessed I had not heard it—I don't remember why I didn't, but he was unfazed. We did not talk long, but we did hit it off. He told me I should come up to visit him at his new institute—the Institute for Society, Ethics and the Life Sciences in Hastings-on-Hudson, New York, just north of Manhattan. I said I would. And about a month later I did.

I met a number of people during that visit: a tall, striking physician named Willard Gaylin; a serious-looking and serious-sounding scholar named Robert Veatch (who turned out to have a dry sense of humor, which I discovered after I made it a point to try and get a laugh out of him every day); an engaging and funny biologist named Marc Lappe—he belonged to a tiny set of engaging and funny biologists—and former magazine editors and writers Margaret and Peter Steinfelds, both exceedingly articulate and passionate, who were interested in the interface between religion and medicine. Furthermore, I think a fast-talking woman—Ruth Macklin, a female philosopher and also a member of a tiny category—was also visiting the day I was there, but I am not entirely sure.

At the end of my visit I was offered a job as a general research assistant—helping anyone who needed help. I found what would soon be the more felicitously named Hastings Center to be so intriguing that I accepted. I kept on with my project at Columbia, but now I had found a group of like-minded spirits enthusiastically engaged with ethical issues in medicine, albeit headquartered in the offices of a former dental practice.

Dan and Will were creating something very special. Soon their center moved to an old estate in Hastings-on-Hudson—the Burke Estate. It had been the residence of Mary William Ethelbert Appleton “Billie” Burke, best known as the good witch Glinda in the 1939 film *The Wizard of Oz*. In the back stood a huge copper birch tree, which is where the tree in the logo of the Hastings Center originated. The rambling, worn home was nothing short of a joy to work in. People met in the morning and talked, came down to get the mail at noon (this is all pre-Internet) and talked some more, ate lunch together and talked further, and then came down for tea in the late afternoon in order to end their day talking. Coming in on the weekends was common, although if you did, you had to handle inquiries from fans who drove to the estate not for bioethical counsel but to learn more about one of the stars of *The Wizard of Oz*.

There is much to say about the history of the Hastings Center, but not here. For that is the start of a long, intellectual, sociological, and policy road down which many traveled. For me, the final steps in my engagement with bioethics were cemented by two amazing mentors—Dan and Will.

Dan was the writer, or, rather, the writer concerned with detail and precision. Not an academic, Dan, with his Ph.D. degree barely in hand, had fled the Harvard philosophy department in abject horror. He was a budding intellectual who passionately believed in writing clearly and cogently for all manner of audiences. To the extent that I can write, it is a direct result of Daniel Callahan editing every written word I sent to him, from manuscripts to memos to lunch orders.

Will was the public face of bioethics or, rather, the first bioethicist to take the subject public. He wrote, but, unlike Dan, he was very much taken with contemporary events, case studies, stories, and narratives. I watched Will closely as he brought bioethics into the public realm. To the extent that I have been able to drive the field into the public arena, it is as a result of having been exposed to the early efforts that Willard Gaylin made when I was at Hastings.

So there you have it—my entry into bioethics was shaped by four key mentors: Ernest Nagel, Bernard Schoenberg, Dan Callahan, and Will Gaylin, and many others who played a role as well. Due to the first two, I have always felt a link to the academy and the university. Due to the latter two, I have always felt a commitment to interdisciplinary work, clarity in writing, and bringing bioethics to the public.

Undoubtedly, each of my mentors would find some fault with what I have done in the decades since I encountered them. They all had strong views about what I should do to build a career. In my view, though, the best way to use strong mentors is not to strictly follow their advice but to balance what you think you want to do against what they think you ought to do. I felt that moving bioethics into the public arena was critical for the field to flourish and have impact. None of my mentors did. Many of my peers felt that democratizing bioethics through the media was wrong-headed and worse. I knew from my mentors there would be a price to pay if I pushed down that road, but it is one that I gladly paid since my intuition was right—bioethics had to be more than a purely academic exercise. The public had to be engaged and the media was the only tool available to engage it. Yet, to flourish in my own career I also knew that I needed an academic home. Some of my mentors did not agree. I felt a medical school was the place to be since that is where the real bioethical action was to be found, standing could be secured for a new discipline, and it is where independent commentary from a non-doctor philosopher, albeit a friendly one, was of direct value. Having built major programs at two medical schools and now in the middle of building another, I heard my mentors, weighed their opinions, and then and only then decided on what was best for me and the field. Training young people, as young as high school age, right through medical school, law school, and graduate school was the lifeblood for the field. I believed that at the start of my career and believe it more firmly today. I am extraordinarily happy that I had the good fortune to encounter and learn from each of my mentors. But while they taught me a great deal they also showed me through their personal example the importance of taking a risk, following your beliefs, and being willing to operate outside the mainstream consensus. Each of them in their way had done that in their own work.

Now you know that there are obvious personal reasons in my life that inexorably led me toward bioethics. Now you also know that the key to being able to make my way down a tiny, barely carved-out path in an emerging new field was having had supportive, smart, and very tolerant mentors.