

On Being a Bioethicist (review)

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➡ For additional information about this article https://muse.jhu.edu/article/308 On Being a Bioethicist: A Review of John H. Evans *Playing God?: Human Genetic Engineering and the Rationalization of Public Bioethical Debate. University of Chicago Press, 320 pp., \$54.00 cloth; \$20.00 paper.*

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John Evans's ironically entitled Playing God? deserves a place on the bookshelf of every bioethicist, alongside Albert Jonsen's The Birth of Bioethics (Oxford University Press 1998) and David Rothman's Strangers at the Bedside (Basic Books 1991). All three volumes focus on the birth, rapid growth, and extraordinary success of American bioethics. Although their accounts differ significantly, the three authors underline several phenomena as pivotal to the development of bioethics: the research scandals of the 1970s, the congressional investigations and government commissions that responded to them, the placement of philosophers on these commissions, the subsequent displacement of the discourses of medicine and theology by a new "bioethical" discourse that draws heavily on argument forms and discourse styles derived from analytic philosophy, and the dissemination of this discourse through The Belmont Report and Tom Beauchamp and James Childress's Principles of Biomedical Ethics. Rothman's tale is perhaps the best told, although as a first effort it still leaves a great deal to be said. His title is a double entendre encapsulating his core contention that, as physicians and medical researchers grew more powerful and more fixated on technology, they became alienated from their patients and thus "strangers at the bedside." The resulting social vacuum was filled by an amalgam of lawyers, philosophers, and theologiansformerly strangers to the bedside-who occupied the social space vacated by physicians and researchers. Rothman concludes that the arrival of bioethicists at the bedside and in policy-making committees reflected a fundamental shift in biomedical decision making, from the private domain of medical and scientific elites to publicly accountable fora such as law courts, presidential commissions, and ethics committees.

Jonsen, the first person ever to be denominated a "Professor of Bioethics," opens *The Birth of Bioethics* with an account of his own transformation from Jesuit priest to bioethicist. The genesis of his book was a conference to which Jonsen invited "many of the pioneers of bioethics." "Their stories about the origins of the field" served "as the building blocks of [his] book," which often reads like a collective autobiography, with Jonsen acting as amanuensis. Yet, despite its distinctly personal flavor, Jonsen's impressively comprehensive chronicle of the rise of bioethics, from its tentative beginnings in a few casual conversations to its formal institutionalization in centers and institutes, is remarkably authoritative. Like Rothman, Jonsen traces the origins of bioethics to the excesses of an exponentially expanded, publicly funded, technologically driven biomedicine running amuck in self-importance even as it was increasingly run as a private fieldom by unelected, unaccountable, and unresponsive elites. Since the new scientific-medical elite resisted calls for accountability by public-funding sources, these public-funding bodies reciprocated by funding a new field, bioethics, whose mission was essentially democratic: holding the biomedical elite accountable to the values and interests of patients and the public.

Jonsen presses his account beyond Rothman's by raising a pivotal question: Why did patients and the public attempt to control the medical-scientific elite by turning to ethics, that is to philosophers and theologians-generally dismissed by Americans as arcane, overly abstruse, socially and political irrelevant, feckless intelligentsia-rather than to lawyers and to the law? Jonsen theorizes that the recruits for the new discipline of bioethics were drawn from elements of the liberal intelligentsia empowered and energized by the civil rights and antiwar movements. As they gravitated toward medicine, these intellectuals naturally transported the moralizing language of these movements into the clinic and onto government commissions, moving, as it were, from civil rights to patients' rights. The American public and public agencies, in turn, were responsive to this discourse of ethical critique because of an entrenched moralizing tradition inherited from America's Puritan past, because American liberalism is melioristic and reformist, and because the critique evoked such precepts as "autonomy," which appeal to the spirit of individualism that lies at the core of the American moral tradition.

Although he does not mention either Jonsen or Rothman by name, Evans expressly dismisses "expanding democracy" accounts of the birth of bioethics—the received accounts of the origins of the field—as genesis myths proffered and accepted to further legitimize the bioethics profession. In fact, Evans argues, bioethics prospered not because it democratized biomedical-moral debate but because it bottled up debate in government commissions and in federal agencies, thereby preventing democratic discussion of the morality of biomedicine and biomedical research in truly democratic bodies, such as legislatures. Now a professor of sociology at the University of California, San Diego, Evans started to think about these issues while writing his undergraduate thesis at Macalester College. His reflections later became the basis of a graduate thesis at Princeton University, which he sharpened during a postdoctoral stint at Yale. The persuasiveness of Evans's account rests on the impressive depth of sociological analysis reflected on almost every page; yet, ironically, his analysis is also blinkered by its sociological origins and hobbled by the very methodology that lends it legitimacy.

There is both a conceptual and an empirical core to Evans's analysis. The conceptual core derives from Max Weber and Jurgen Habermas's distinction between formal and substantive rationality. An action, analysis, or argument is held to be formally rational if it deals with assessing the best means to some generally accepted and often unstated end or limited set of ends. Formal rationality is the "thin" form of rationality manifest in cost/benefit calculations and risk/benefit analyses. Substantive rationality, in contrast, is "thick": it deals with multiple ends, values, lifestyles, or forms of life (e.g., a Buddhist, Christian, Jewish, or Muslim form of life). Substantive debates thus center on the worthiness of ends and the compatibility of various means with these ends. Moreover, means found incompatible with substantive ends tend to be rejected summarily, irrespective of the consequences. For example, the claim that some assisted reproductive technologies, such as cloning, affront human dignity by transforming human nature into an artifact will be seen as justifying a ban on the technology, irrespective of the consequences. For Weber, and later for Habermas, the development of the bureaucracies essential to the creation and functioning of modern capitalist states and their economies depends upon the triumph of formal over substantive rationality. Thus, as market mechanisms and state organizations colonize increasingly large swaths of contemporary life, formal rationality displaces substantive rationality, leaving individuals and the public virtually no space to contemplate the validity of ends-or so Habermas fears.

In Playing God? Evans applies the Habermas-Weber analysis to bioethics. A scholar trained in the humanities sis a priori, citing a few specimen quotations here and there to substantiate it. Evans sociological training leads him to offer a more empirical and ultimately a more authoritative approach. As the subtitle of his book indicates, he analyzed the public bioethical debate between 1959 and 1995, downloading almost 52,000 items from the National Library of Medicine's Bioethicsline and ultimately analyzing the 989 items that had as their primary topic "genetic intervention, gene pool, gene therapy, or germ cells." Supplementing these materials with those indicated in bibliographical resources from the Hastings Center and Library of Congress, Evans ultimately analyzed a "universe of 1,465 items published between 1959 and 1995" on human genetic engineering. He then divided the articles by five time periods, identifying debating communities (communities of authors debating a given subject) and tracking citations to identify influential texts. Using cluster analysis and similar techniques, Evans arrives at a conclusion that anyone in the field will immediately accept and then turns in a direction that many will find unacceptable.

The acceptable conclusion is that bioethical and philosophical discourse has displaced the discourse of theologians-and, to a lesser extent, that of scientists-in the human genetic-engineering debate. After demonstrating that theological discourse throughout the debate remained substantively "thick" while bioethical discourse quickly became formally rational and "thin," Evans then argues that the thin formal rationality of bioethics is precisely the reason why bioethical discourse displaced theological discourse. Bioethics succeeded because, in substituting thin, formal rationality for thick substantive debates over ends, it made itself amenable to the bureaucracies that control purse strings and make public policy.

The government agencies that commissioned the debates over human genetic agencies require formally rational argumentation in order to function. Substantively rich theological discourse was useless to them unless it was translated into formally rational discourse. So commissions and agencies turned to bioethicists to translate the thick substantive reasoning of the theologians into the thin, formally rational discourse of bioethicists-thereby reinforcing the predominance of bioethics. The ironic title of Evans's book refers to this "translation" project, specifically to one section of the 1983 President's Commission report *Splicing Life* that unpacks, defuses, and ultimately dismisses objections to human genetic engineering implicit in the metaphor "playing God."

The "Playing God incident" illustrates yet another reason why, according to Evans, bioethicists dominated the human genetic-engineering debate. Although envisioning themselves as watchdogs protecting the public against the scientific elite, bioethicists' predilection for thin formal reasoning transformed them into the unwitting lapdogs of the research establishment.

Looking back over the first thirty years of the [human genetic-engineering] debate, we see that the alliance with the profession of bioethics has also forwarded scientists' interests quite well. In the area of [human genetic engineering], there seems not to have been a single moment when a mainstream scientist wanted to conduct an experiment and bioethicists said no. Individual scientists have been slowed, but only out of concern for safety (nonmaleficence) which is consistent with the interests and beliefs of the scientific community. This is due not to some moral failure on the part of individual bioethicists, but rather to the form of argumentation that has been encouraged by the environment of government advisory commissions. There is almost no way within their form of argumentation to challenge the use of any means if it can be shown to forward beneficence and nonmaleficence. There is also no way to set alternative ends that could be used to challenge the desires of scientists. (195)

Evans believes that the triumph of formal rationality is regrettable because "substantively rational debate about what a country should do is critical for any democratic country." For, "if we cannot have substantive debate, we become slaves to the means that we ourselves have produced." "We need thick public debates about ends," Evans argues, "as well as thin debates about how to advance these ends, once they have been agreed upon by the public" (197). Of course, Evans admits ruefully, in a sense we already have such debates; they are held in bodies called "legislatures."

I was taught philosophy by logical positivists (although the movement had mellowed into "logical empiricism" by the time I arrived on the scene). My teachers were advocates for the thin formal rationality deplored by Evans. Fugitives from fascism and from the thick substantive rationality promulgated by Martin Heidegger and other pro-Nazi academics, my teachers dismissed Heideggerian musings on the ends of technology as antidemocratic humbug. Yet they were also well aware of the limits of formal rationality. Herbert Feigl liked to tell his students the tale of the drunk and the lamppost. A good Samaritan seeks to assist a drunk searching for something under the lamplight. "What are you looking for and where did you lose it?" asks the Samaritan. "I lost my keys over there," responds the drunk, pointing away from the lamppost into the darkness." "Why are you searching under the lamppost?" queries the perplexed Samaritan. "Because the light is better here," replies the drunk. Feigl's point was that, like the drunk, scientists tend to seek answers in the areas best illuminated by their methodology, even if they suspect the answers that they seek lie elsewhere.

Evans's methodology sheds light so brilliantly that he refuses to consider the world of bioethics beyond the "universe of 1,465 items published between 1959 and 1995" and the realm of government commissions. He excludes from consideration, by methodological fiat, foundational bioethics (thereby excluding the substantive concerns of someone like Englehardt in the two editions of *Foundations of Bioethics* [Oxford University Press 1986, 1996]) and clinical ethics, preferring to deal only with "public bioethical debate where social elites . . . debate over what society should do" about such issues as human genetic engineering (34). Bioethics is thus portrayed as a profession whose "work" is the production of arguments about what society ought to do; and he considers it successful just insofar as society's representatives—that is, government

commissions-accept its arguments and its way of framing arguments. Bioethicists, moreover, are limited to those professionals "who use the profession's form of argumentation." For those who, like me, are surprised to learn that there is an official form of professional bioethical argumentation, it turns out to be principlism: either Beauchamp and Childress's quartet of principles, or the Belmont trio. Furthermore, Evans construes principlism (unfairly, in my view) as a thin formalist rationality. It follows from his definitional framework that public bioethics excludes consideration about ends. Evans's analysis thus predicts-and his survey of 1,465 published pieces is said to confirmthat bioethicists' prefer to deal with questions about means rather than with questions about ends; that is, they prefer questions about whether we have sufficient evidence that human genetic engineering is safe, to such questions as whether we should engage in human genetic engineering.

Can it really be the case that bioethics-or, at least, public bioethics-never considered the question of whether human genetic engineering is morally permissible? Were not these questions addressed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its 1983 report, Splicing Life: A Report on the Social and Ethical Issues of Genetic Engineering with Human Beings? Evans argues that they were not addressed. Yet Al Jonsen, who was one of the Commissioners, believes that they were addressed. The issue is framed in terms of a discussion of a letter to President Jimmy Carter from the General Secretaries of the National Council of Churches, the Synagogue Council of America, and the United States Catholic Conference, which Carter forwarded to the Commission. Jonsen quotes this letter at length.

We are rapidly moving into a new era of fundamental danger, triggered by the rapid growth of genetic engineering. Albeit there may be opportunity for doing good; the very term suggests danger. Who shall determine how human good is best served when new life forms are being engineered? Who shall control genetic experimentation and its results which could have untold implications for human survival? Who will benefit and who will bear any adverse consequences, directly or indirectly? These are not ordinary questions. These are moral, ethical and religious questions. They deal with the fundamental nature of human life and the dignity and worth of the individual human being (Jonsen, 185).

The letter also included the line "Those who would play God would be tempted as never before," which, Jonsen reports, sounded like a "clarion for another crusade like that [conducted by creationists] against the evolutionists." (In fact, Jonsen's observation was astute: "playing God" has been the rhetorical tag of choice in the religious right's condemnation of various forms of assisted reproductive technologies and genetic interventions.)

Despite apprehensions about the religious community's motives, the Commission met with theological representatives of the groups who wrote the letter. The upshot was not confrontational for the following reason:

Biblical religions teach that humans are, in some sense, cocreators with the Supreme Creator . . . [and thus] respect and encourage knowledge about nature, as well as responsible use of that knowledge. Endorsement of genetic engineering, which is praised for its potential to improve the human estate, is linked with the recognition that the misuse of human freedom creates evil and that human knowledge and power can result in harm. (quoted at Jonsen, 186)

The Commission also noted that Pope John Paul II in addressing genetic scientists *approved* genetic science

when its aim is to ameliorate the condition of those who are afflicted with chromosomic disease. . . . I have no reason to be apprehensive for those experiments in biology that are performed by scientist who . . . have a profound respect for the human person, since I am sure that they will contribute to the integral well-being of man. (quoted at Jonsen, 187)

Jonsen portrays the Splicing Life report as a reasonable effort to understand and to address the concerns raised by the theologians. He remarks with pride that "the final report contained lucid discussions of obscure concepts such as "interference with nature," "creating new life forms," "the malleability of human nature," and "the sense of personal identity." In his view the Commission considered and addressed the issues raised by the religious leaders, concurring, in effect, with Pope John Paul II that experiments designed to create the capacity to prevent and cure genetic disease were permissible, provided that they were conducted under the careful oversight of the National Institutes of Health's Recombinant DNA Advisory Committee. Thus, as Jonsen relates the story, the Commission carefully considered questions of the permissibility of human genetic engineering, weighed the fears of religious leaders, and yet still found that experiments aimed at creating a capacity to prevent and cure genetic disease could continue under close supervision.

Evans would have us believe that both Jonsen, an erudite scholar stepped in the moral theology and a former Jesuit, and Pope John Paul II were so thoroughly seduced by thin, formal rationality that they could not consider such a basic issue as whether or not human genetic engineering was an end worth pursuing. Evans here succumbs to what I call "debater's fallacy." In a debate one can, and often should, challenge anything and everything. Normally, however, moral deliberation, like normal science, proceeds incrementally. Core beliefs and previously accepted positions are seldom challenged without some compelling reason. Discussion thus occurs at the edges. The major Western religions have long since reconciled themselves to the idea that medicine serves a human good. It was thus religious leaders like Cotton and Increase Mather who led the proinoculation side of the Colonial debate over small-pox inoculation. Since that time the value of the therapeutic ends of medicine has not been questioned by mainstream Western religions. Consequently, as Pope John Paul II quite properly observed, insofar as molecular biological interventions at the genetic level are indistinguishable from other biochemical medical interventions (drugs, hormones, and so forth), they should be considered no more morally problematic than other interventions.

It was not the Commission's task, therefore, to reconsider whether medical therapies constitute a human good. There was no need to question the idea of gene therapy unless opponents of human genetic engineering could demonstrate that gene therapies would potentiate some danger, harm, or evil that would outweigh the potential good that they could do. The opposition failed, not because Jonson or Pope John Paul II were somehow disinclined to employ substantively thick reasoning about ends, but because there was already a consensus about ends and because vague metaphorical language is insufficient to outweigh research that could offer significant opportunities to ameliorate human suffering.

Evans's deepest concern is that insofar as bioethics serves as the handmaiden of government agencies, it preempts democratic debate about ends. Yet American political philosophers, from John Rawls to Robert Nozick, have argued that unlike totalitarian and theocratic regimes it is not the business of liberal democratic governments to determine the appropriate ends of life. In separating church from state, in creating zones of personal liberty, privacy, and social freedom, our form of government leaves such decisions to individuals and to the communities they create and inhabit. It is thus not the role of government to determine whether people accept the good of medical treatment. In fact, in Cruzan the Supreme Court upheld the right of individuals to refuse life-sustaining treatments (including even nutrition and hydration). Similarly, insofar as public bioethics addresses democratic governmental bodies, it is not bioethicists' function to discuss ends per se.

Bioethics, however, is more robust than the thin field that Evans refers to as "public bioethics." In the spirit of Socrates, bioethicists wander outside of academia. They are found in hospital corridors, in laboratories, and in corporate boardrooms; they discuss, opine, and lecture in churches; they serve as talking heads on television; and they write newspaper columns. They even organize to facilitate healthcare reform (for example, Oregon Health Decisions, which helped create Oregon Medicaid Reform) and to challenge laws promulgated by bioethics commissions (as I once did; see, Robert Baker and Martin Strosberg, *Legislating Medical Ethics*, Kluwer 1995). Bioethicists continually foster public debate over bioethical issues, and in so doing most bioethicists consider precisely the questions about ends that Evans claims we eschew.

I will cite but one example. I have on my desk a splendid volume on human genetic engineering written by four bioethicists who served on government advisory commissions (one even served as advisor to the President's Commission during the period that it wrote *Splicing Life*). Evans's model predicts that they would approach the subject in terms of thin rationality-discussing only questions of helping, not harming, safety, and so forth. In fact they open the volume with a discussion of "Genetic Communitarianism," "The Quest for the Perfect Baby," and "Genetic Enhancement Certificates"; then, after discussing the history of eugenics, they raise questions about genetic justice, treatment versus enhancement, and genetic perfectionism, among other things. In short, they discuss endsvigorously questioning potential forms of life—straightforwardly, without using obscure or vague metaphors. The book, *From Chance to Choice: Genetics and Justice* (Cambridge University Press, 2000) by Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler, demonstrates that bioethics is properly concerned with ends—we just attempt to say what we have to say clearly, which is a prerequisite for informed democratic debate.

It is one thing to dispute Evans's insightful analysis of public bioethics after reading his critique and yet another to imbibe his work secondhand from reviews such as this. Evans's critique of the role of public bioethics is insightful and worth pondering directly. If he misses the mark, he nonetheless comes close enough to the heart of the subject to deserve a careful reading by everyone in the field. *Playing God?* as I said earlier, merits a place in the library of everyone interested in the past and future of bioethics, alongside one's copies of Jonsen, Rothman (and, I might add, Buchanan, Brock, Daniels, and Wikler).