

The History of Bioethics: Its Rise and Significance

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Introduction

Bioethics, the unique conceptualizing, analyses, and managerial methods that arose in response to discomfiting postwar developments in biology, medicine, and biotechnology, spawned a new profession and seeded novel social institutions.¹ It has sown think tanks, educational programs or courses in universities, law and medical schools, hospital consultancies, research review committees, national policy commissions, professional associations, and generated a massive publication roster. A historiographic account of the unprecedented emergence and endurance of these phenomena awaits a body of publications based on meticulous research of the sprawling arenas into which bioethics expanded: clinical consultation, research oversight, public policy recommendations, and cultural influence.² So far, professional historians have not systematically mined archives to produce a sizable body of such research. Most accounts of bioethics' 'birth' have been penned by bioethicists themselves or by social scientists, some of whom were embedded with individuals who, as the field came into bold relief, became bioethicists.³ Even so, this article will characterize bioethics' rise in the United States and its cultural significance.

For bioethicist cum historian Albert Jonsen, early bioethicists were 'pioneers' who "blazed trails into a field of study that was unexplored and built conceptual roads through unprecedented problems." The field began as "an amorphous expression of concern about the untoward effects of advances in biomedical science and gradually form[ed] into a coherent discourse and discipline" (Jonsen, 1998: p. viii). The 'show-pieces of bioethics,' according to Jonsen, are the products of the national commissions which "radically change[d] the practice of scientific research in America" (Jonsen, 2001: p. 44). The labor of early bioethicists yielded intended results that the new profession often celebrates (Fox and Swazey, 2008: pp. 123ff). Evidence suggests, however, that 'mainstream' bioethics' legacy includes at least three notable collateral social transformations.⁴

First, it assisted in defusing incendiary political assessments about science and technology read widely during the 1950s and 1960s. It transformed political critique into an ethical query that facilitated civic management through guidelines and regulations rather than activism or advocacy. This transformation served to midwife technologies, then considered exotic and problematic into broad social acceptance.⁵

Second, it delegitimated religious counsel, prioritizing secular guidance based on principles culled from a presumptive universal or 'common morality' (see, for example, Engelhardt, 2003; Evans, 2002; Moreno, 2005). This mediated a secular society's need for moral resolution in the face of bewildering biomedical developments and, as with the quelling of radical political critique, it enabled civic oversight of biomedical research.

Third, along with other developments altering the professional culture of science, e.g., the rise of science entrepreneurs, (Press and Washburn, 2000) the institutionalization of bioethics contributed to the dissipation of the postwar responsible science movement's influence. That influence saw a subsection of scientists and physicians seeking public involvement in interrogating research trajectories or clinical practice that they themselves found troubling. Instances of scientists or physicians seeking (nonbioethics mediated) public awareness or counsel about moral hazards accompanying technological developments largely subside with the bureaucratization of ethical scrutiny.⁶ The emergence of an infrastructure of bioethical examination (e.g., committees, commissions, guidelines, and regulations) assisted in disciplining professional discourse as well as framing public understanding.

Recent developments reveal these transformations to be dynamic and changing. The success of the political right in influencing bioethical debate at the turn of the twenty-first century resulted in the fracturing of bioethics' civil discourse based on principles asserted to have been universal. It exacerbated fissures across a liberal-conservative spectrum nascent within the profession but previously found manageable. Some commentators view the profession's function as secular arbiter of moral questions pertaining to science, medicine, and

¹ The term 'profession' is used loosely. For a consideration of professionalization in the context of bioethics, see Bosk (2008a): pp. 21–37. Bosk objects to licensing and certifying ethics consultants. See also, Wolpe (2010): pp. 109–118 (despite his mischaracterization of this article's author as 'from the right,' p. 116). Wolpe predicts, "the future will see a new class of bioethicists with more firmly established professional identities" (p. 116).

² For an analysis of these categories, see Evans (2012a): pp. xxvii–xxxv.
³ Accounts of the rise of bioethics from members of the founding generation include Jonsen (1998), Levine (2007), Callahan (2012), Drane (2012). Accounts from embedded social scientists include Rothman (1991) and Fox and Swazey (2008). On the topic of history and bioethics, see Rosenberg (1999), Brandt (2000), Belkin and Brandt (2001); Baker (2002), Stevens (2003), Short (2003), Belkin (2004), Wilson (2011), Emmerich (2011), and McWhirter (2012).

⁴ A number of commentators have begun referring to 'mainstream' bioethics as a way of distinguishing it from bioethics as practiced by those who influenced federal policy making in more religious ways as the 'culture wars' came to into effect. The term may also serve to distinguish feminist bioethics and 'critical bioethics' (see below) from the bioethics of the founding generation. Unless otherwise specified, the term 'bioethics' is meant to convey mainstream bioethics.

⁵ (Stevens, 2000). See also Bosk (2010), who writes that we need to understand "...how ethical expertise is deployed to transform social spectacles into organizational routines" (p. S143). Stevens' critique has received a number of critical reviews from bioethicists. See, for example, Jonsen (2001) and the author's rejoinder, Stevens (2001).

⁶ This observation warrants further investigation. See Stevens (2000) for a discussion that locates the modern roots of bioethics in the legacy of the responsible science movement. Also relevant is Evans' consideration of how scientists sought to regain control of the debate over human genetic engineering by 'thinning' public discussion so as to avoid deliberation on the eugenic ends of genetic manipulations, shifting to talk of 'gene therapy' rather than genetic engineering (Evans, 2002). Distinguishable from the responsible science movement ethos are the 1975 moratorium on rDNA research (Asilomar) and the 2012 moratorium on genetically engineered H1N1 bird flu virus research. These are instances of scientists trying to subdue public concern, not generate public awareness or elicit debate.

biotechnology to be in jeopardy. Some bioethicists have called for a 'progressive bioethics' to counter the power and influence of their conservative and neo-conservative counterparts.

Historical Roots

The word 'bioethics,' coined in the early 1970s, congealed into a narrow definition following contested consideration of alternative meanings.⁷ Wisconsin cancer researcher, Van Rensselaer Potter had urged using the term to signify ethical analysis of health, well-being, and global survival understood as a webbed function of human beings interconnected with their environments. Instead, early bioethicists favored the more constricted concept, and by extension the more constricted remit, suggested by the Kennedy Institute of Ethics. This designation tended to limit ethical evaluation to moral dilemmas affecting human beings in medicalized settings. Often these dilemmas were seen as accompanying technologies then considered exotic and usually inexorable, including organ transplantation, renal dialysis, genetic screening, mechanical respiration, *in vitro* fertilization, etc. The narrower definition reflected the distance of the fledgling profession from the more far-reaching, institutionally challenging influences of the environmental movement then also underway and tended to foster professionalization over activism.⁸

A chronology of some milestone events suggests how the 1970s is the decade of bioethics' foundational flowering. The world's first bioethical 'think tank' institutions, The Hastings Center and the Kennedy Institute of Ethics, debuted in 1969 and 1971, respectively. The first of a continuing series of federal bioethics commissions convened in 1974. The influential *Belmont Report*, which adumbrated foundational principles and promulgated guidelines for human experimentation, appeared in 1978. The same year brought *The Encyclopedia of Bioethics*. The keystone text, *Principles of Biomedical Ethics*, was published in 1979 and helped secure the workability (though not uncriticized) of 'principlism,' the idea that 'universal' ethical principles could bring resolution to morally unsettling cases. Institutionally, bioethics is a product of the 1970s. Its historical influences, however, reach further back. In fact, the rise of bioethics bears a systemic marker of American history, implicating a sociocultural impulse stretching back as far as the nation's founding. That impulse is the recurring cycle of emerging and dissolving ambivalence toward 'progress' found within a culture otherwise profoundly devoted to it.

⁷ Reich, 1995; Whitehouse, 2003. See also, Van Rensselaer Potter, *Fragmented Ethics and 'Bridge Bioethics'* (1999). Although, see Goldim (2009), who credits Fritz Jahr with coining the term in (1927). Twine (2005) seeks to reestablish the relevancy of Potter's "vision for a mutually intertwined...medical and (original italics) ecological bioethics" (p. 285).

⁸ Warren Reich asserts that *originally* (emphasis added) the Hastings Center had favored a broader scope, one that went beyond ethical issues in medicine to include an ethics of the life sciences that included environmental health among other areas (Reich, 1995). Much depends on how one understands what is meant by 'originally.' For a chronicle of the Hastings Centers' struggles to develop its expertise and professional reach, see Stevens (2000). Additionally, Reich distinguishes 'three senses' of the work 'global' and parses the ways in which the Hellegers/Kennedy Institute approach was 'global.' See also, Walters (2003), which includes an account of the Kennedy Institute's international reach.

Like its historical analogs, the founding generation of bioethicists expressed deep concern over unrestrained technological (in this case, biomedical) 'advances.' Ambivalent social actors constitute an educated elite subsection of a larger class that otherwise celebrates the indicators of 'progress,' including technological progress, especially from the industrial revolution to what some have called the 'biological revolution.'⁹ Such critics, responding with anxiety to what seemed to be inexorable developments, typically did not indict the producers or producing class of the problem causing advances. In important ways, bioethicists resemble the 'antimodernists' identified by T.J. Jackson Lears. A diffuse group of individuals from educated social classes active between 1880 and 1920, antimodernists were ambivalent about industrialization's consequences, disapproving but at times eager for the materialist development of which they were critical. Ultimately, antimodernist critique was unable to resist absorption into the dominant culture. Their suggestions, often unintentionally, served to transform older, inhibiting, bourgeois values into programs that eased passage into a more secular, corporate world, supporting consumerist social traits they originally eschewed (Lears, 1981).

Bioethics' more contemporary taproot is grounded in the 1950s and 1960s. A number of bioethicists' autobiographical accounts as well as secondary commentary point to the turbulent 1960s and its hallmark legacies of challenges to authority (e.g., civil rights activism, Vietnam war protests, environmentalism, the 'rights explosion' including, eventually, second wave feminism, patients' rights, and disability rights and the ensuing medical malpractice 'crisis') as being highly influential in bioethics' rise and institutionalization.¹⁰ They point, too, to the consciousness-raising impact of human experimentation scandals from the postwar Nuremberg trials to the infamous Willowbrook case, where institutionalized retarded children were infected with hepatitis, to physician Henry Beecher's 1966 revelations of 22 cases of unethical experimentation.¹¹ There is little doubt that such influences helped form the crucible in which bioethics was fired. If, however, a signature characteristic of early bioethics, namely, the need for extraprofessional counsel in the face of troubling biomedical and biotechnological advances, is traced back to its

⁹ Regarding a 'biological revolution,' see Stevens (2000): pp. 13ff. For the tradition of ambivalence, see Stevens (2000): pp. 1-7. Examples of early bioethical concern over advances in biomedicine abound, e.g., Pellegrino (2003): p. 3; examples discussed in Stevens (2000): pp. 29-32. The analysis offered here does not consider whether the technologies constituting the 'biological revolution' actually were presenting unprecedented moral dilemmas, only that it was the belief of those participating in the early years of bioethics' formation that the technologies warranted sustained attention and debate.

¹⁰ see, for example, Jonsen, 1998; Rothman, 1991; Fox and Swazey, 2008.

¹¹ The human experimentations that called forth the Nuremberg trials seem to have been viewed largely as a function of Nazi evil that did not represent practices typical of professional medical behavior more generally. "The Nuremberg Code," according to law professor Jay Katz, "was relegated to history almost as soon as it was born" (quoted in Fox and Swazey, 2008: p. 26). The Tuskegee scandal, which involved 600 poor and poorly educated African-American men in a syphilis trial, which left many of them untreated, did not come to broad public attention until 1972 - after 'bioethics' already had begun institutionalizing in significant ways. How the scandals that came to light in between these historic markers (Nuremberg, 1947; Tuskegee, 1972) might constitute a *sine qua non* of bioethics rather than an example of the fallacy of *post hoc ergo propter hoc* is a question that would benefit from additional historical scrutiny.

genesis, coming into crisp focus are concerns that emanated first from *within* professional medicine and science.

In the late 1950s and 1960s, physicians distressed by how efforts to save lives often merely prolonged dying, sought guidance from nonmedical sources. In 1957, for example, the International Congress of Anesthesiology queried Pope Pius XII for criteria to determine when resuscitative measures should be used and, importantly, when they should be discontinued. Similarly, at the First National Congress on Medical Ethics and Professionalism in 1966, a conferee admonished his colleagues that the problems that ‘contemporary measures’ were causing, were not medical but theological, social, and legal: “...the team approach of physicians and clergy working together, with patients and family, is the ideal solution to this problem. At times, other professions may contribute...such as lawyer, social worker, or nurse,” he urged (quoted in [Stevens, 2000](#): p. 79).

Scientists, too, sought public engagement. Those seeking to alert the public about the ramifications of what some dubbed a ‘biological revolution’ exhibited sensibilities inspired by the postatomic responsible science movement. Genetic discoveries made in the wake of identifying DNA’s double helix structure meant for some scientists that unlocking the power of the gene might unleash moral dilemmas as had discovery of the atom. Mindful of the atomic scientists who first worked on developing the bomb and later regretted the social consequences of having done so, these biologists wished to ignite public interest.

Genetic scientists at a 1963 Ohio Wesleyan University conference, for example, made the connection clear. For Dr Guido Pontecorvo, “...biologists, and in general all scientists, today have learned from the experience of nuclear energy and are conscious that it is their duty to inform society of the implications of the advances in their own fields” (quoted in [Stevens, 2000](#): pp. 17–18). T.M. Sonneborn’s caution underscored the biological revolution: “Biology has undergone a revolution the scope and impact of which not even the penetrating imagination of Aldous Huxley could sense...New possibilities of controlling human development have emerged” (quoted in [Stevens, 2000](#): pp. 18–19). Salvador Luria implicated the responsibility of scientists to exercise restraint: “The impact of science on human affairs imposes on its practitioners an inescapable responsibility. This responsibility actually affects the course of scientific development: ...it created the urge to seek useful applications ...[O]n the other hand, it may restrain the scientist from pursuing a line of research that is clearly leading to evil applications. The instance of nuclear fission research is a natural illustration of the many moral alternatives that face the natural scientist....” (quoted in [Stevens, 2000](#): p. 17).

Importantly, when calls came from within science and medicine for transprofessional moral counsel, they occurred in a climate where public intellectuals, also affected deeply by the atomic explosion, were offering far more radical critique. These critiques went beyond their predecessors to challenge the political sources and political agenda of scientific research – and they enjoyed a widespread general audience. Lewis Mumford, Herbert Marcuse, Jacques Ellul, and Theodore Roszak offered influential analyses not merely of specific technologies but of ‘technological society.’

Mumford, for example, like a number of other public intellectuals, felt the development and deployment of the

atomic bomb revealed troubling aspects of science in society: “...it was the success of this project that gave the scientists a central place in the new power complex and resulted eventually in the invention of many other instruments that have rounded out and universalized the system of control first established to meet only the exigencies of war” (quoted in [Stevens, 2000](#): p. 21).

The bomb’s development implicated a nonneutral, political dimension of science. Its detonation not only galvanized some scientists to question the uses of scientific research and call for public education and input, it not only ‘radicalized’ public intellectuals, it also infused more popular responses. Gordon Rattray Taylor’s 1968 best selling, *Biological Time Bomb*, for example, charged that, “[t]he explosion of the first atom bomb drove a jagged crack through the superman image [of the scientist].” The taint he cast fell broadly to include biologists, likening them to Dr Frankenstein, charging that too few had been willing to warn the public about the moral hazards of human genetic engineering (HGE) (quoted in [Stevens, 2000](#): p. 26). Historian Donald Flemming’s *Atlantic Monthly* article, ‘On Living in a Biological Revolution,’ was similarly condemnatory. The ‘new biologists’ seek the manufacture of man, he warned. “...The new form of spiritual sloth will be not to want to be bodily perfect and genetically improved. The new avarice will be to cherish our miserable hoard of genes and favor the children that resemble us” (quoted in [Stevens, 2000](#): p. 28). The hostility of such popularized attacks made clear that scientists would not be able to control public response to revelations made by ‘responsible’ geneticists.

Institutionalizing: Three Examples from History

Those who would become bioethicists considered biomedical agenda and the biological revolution in a society transformed by these dynamics. Would society correct power imbalances and social injustices identified by critics, or would it absorb denunciations and continue undeterred? The role that bioethics came to play in mediating that outcome is a question for continuing historical analysis. The question should be understood not only as what role bioethicists intended for themselves, but also how and why bioethics was selected for institutionalization by biomedical power structures and society more generally. There is social scientific research and interpretation to date suggesting that much of the critical impulse giving birth to bioethics was absorbed as the field institutionalized – though not without altering the political culture into which it was infused. Additionally, calls for a more ‘critical’ bioethics have grown to modify that absorption (see below). Windows on the question of how bioethics developed to negotiate the crevices between biomedical hegemony and ‘outside’ civic authority during bioethics’ institutionalizing decade of the 1970s are provided through a consideration of three developments: the early experiences of the first bioethics institute, the Hastings Center; the introduction of nonphysician decision makers into the contested clinical space of neonatal intensive care; and finally, political-cultural dynamics of early bioethics commission work.

Launched in New York in 1969 by philosopher Daniel Callahan and psychiatrist Willard Gaylin, it was important to its

founders that the institute (that was later to become the Hastings Center) be independent.¹² They rejected university affiliation and, initially, would seek funding only from foundations, the government, or philanthropists in order to avoid corporate influence. Its first financing was a loan from Callahan's mother. By the end of the first year they had won grants from John D. Rockefeller III, Elizabeth K. Dollard, the Rockefeller Foundation, and the National Endowment for the Humanities.

Callahan's 1971 assessment suggests how the novel idea of creating an institute to investigate the "ethical impact of the biological revolution" was in demand: "We receive an average of 10 inquiries a day, requesting information on the Institute itself, or one of our programs. The greatest stimulus for this has come from a number of news stories about the Institute..." (quoted in [Stevens, 2000](#): p. 48 and p. 54, respectively). By 1974, the Hastings Center (HC) had achieved stability after doubling its budget every year, operating on a \$1 million budget by 1977. But the Center came to realize that even noncorporate funding was problematic. Funding agencies typically wanted specific questions addressed and problems solved. As a contact at the US Department of Health, Education, and Welfare instructed in 1971, "Unless Institute endeavors can be focused not only on analysis of problems, but also on their resolution, public administrators...are not going to be very interested in the Institute." But as HC fellows understood, this would leave 'troublesome underlying problems' unexamined ([Stevens, 2000](#): pp. 65–66). They came to understand this more directly in 1975 when the National Institutes of Health (NIH) rejected an HC application to renew a grant to study the ethical, legal, and public policy implications of genetic technologies and their human applications. The application was rejected, in part, for having an 'antitechnological' bias and exhibiting a prioritization of individual rights over the 'greatest good for the greatest number.' The NIH also criticized the HC for not giving out guidelines to assist screening agencies ([Stevens, 2000](#): pp. 69–70).

Its early years saw the Center struggling over whether and how activist it should be. The meaning of 'activist' ranged from holding press conferences to expose ethical abuses, to proposing legislation, to recommending guidelines, to simply deliberating about ethical abuses and possible solutions. Founders were particularly challenged by an increasing number of demands to expose the abuses they encountered and go farther in promoting their various recommendations. Critics urged, "Why don't you get out of the ivory tower and into the streets?" "You people should quit talking and get some laws passed" (quoted in [Stevens, 2000](#): p. 57). The Center was being called upon to function as an advocate. But the HC also had to contend with charges of being 'antiscience,' or 'antitechnological,' or 'anti-medical.' In 1971, for example, the clinical director of the National Institute of Allergy and Infectious Diseases told the Center that its members were 'negative' and should have "spent more time...trying to find out how society and the individual might be improved" (quoted in [Stevens, 2000](#): p. 60).

Ultimately, an adversarial role was rejected. The Center's modus operandi became to accept grant money to create

'guidelines' for specific projects. It would proffer suggestions for how to use a technology presumed to be going forward. So, for example, while it would publish guidelines for how to proceed with mass genetic screening, the Center would not join a law suit brought by a number of 'black groups' challenging mandatory screening of school children for sickle-cell anemia. Requests to participate in legal actions were considered problematic and discouraged. Another strategy, understood at the time to be 'establishmentarian,' was the decision to counsel medical and scientific professionals rather than to address the general public. Such strategies were undertaken to avoid a 'factionalizing' of HC fellows and to cultivate a 'nonideological' reputation. Together with the effects of funding constraints, these strategies fostered discourse and methods that supported a process-oriented type of ethics management, rather than substantive challenges to the sociopolitical sources and function of specific technologies or the legitimacy of biomedical power and authority more generally ([Stevens, 2000](#): pp. 56–59).

The second historic example concerns the public debate that ensued in the 1970s over when to start or end heroic measures for premature infants or newborns with disabilities. How to cope with the tragedy of severely damaged or suffering newborns was not a consideration unique to the 1970s nor, in fact, has it ended (see, for example, [Wesolowska, 2013](#)). That decade did, however, see unprecedented public exposure of clinical practice and turmoil on that subject. The case of 'the Johns Hopkins baby,' in particular, ignited public concern. In 1969, the parents of a baby with Down syndrome refused to give permission for surgery to repair a correctible intestinal blockage. Placed in the corner of a nursery, the infant starved to death over 15 days. Although the case was in the opinion of a number of Johns Hopkins physicians not so unusual, it deeply disturbed a number of hospital staff who, according to historian David Rothman, "took the issue outside the hospital" (see 'No One to Trust,' Chapter 5 in [Rothman, 1991](#)). A film about the incident garnered such moral indignation and bad press for the hospital that Johns Hopkins' directors defended by announcing that they would create an interdisciplinary review board to advise on difficult cases ([Rothman, 1991](#): p. 193).

Some physicians came to feel that new decision-making strategies were in order. The way one doctor viewed it, "Here we are really playing God and we need all the help we can get. Apart from giving parents a voice – or at least a hearing – we should enlist the support of clergymen, lawyers, sociologists, psychologists, and plain citizens who are not expert at anything, but can just contribute their common sense and wisdom" ([Rothman, 1991](#): p. 196). But, at this time, authority to call for such assistance emanated from the physician. It was not a matter of parental prerogative to insist upon it.

By 1973, however, developments unrelated to neonatal crisis care, per se, but with far-reaching political ramification devolving on individual rights, came to affect analyses of who should count as medical decision makers. *Roe v. Wade*, which legalized abortion, worked, according to Rothman, to "...maximize parental autonomy in that a mother who wanted a fetus aborted had the right to do so.... Under *Roe v. Wade* the parent determined whether the fetus would survive – it was not much of an extension to add, whether a defective newborn would survive" ([Rothman, 1991](#): p. 204). The emergent disability rights

¹² Initially dubbed Center for the Study of Value and the Sciences of Man in 1969, it was changed to Institute of Society, Ethics and the Life Sciences in 1970, and subsequently to, The Hastings Center.

movement also contributed to an expanded view of who should be making decisions on behalf of whom, although sometimes in tension with parental prerogative. Section 504 of the Vocational Rehabilitation Act in 1973, which banned discrimination on the basis of 'handicap' was particularly influential in how the debate shifted. The 'prerogatives of doctors or parents' were not the sole concerns. The rights of newborns with disabilities now also needed to find expression and, for some, this required the implementation of a review board.

Rothman concludes that the era of unilateral decision making on the part of physicians in the nursery had come to an end. But the ethical apparatus brought to bear on these anguishing cases constituted a type of oversight that would leave unexamined broader social questions, e.g., "...are expenditures on the neonatal nursery the best use of social resources, or, why are most babies in the neonatal nursery from underprivileged families?"

For Rothman, "...the Johns Hopkins case helped ensure that philosophy, not the social sciences, would become the preeminent discipline among academics coming into the field of medicine. This, in turn, meant that principles of individual ethics, not broader based assessments of the exercise of power in society, would dominate the intellectual discourse around medicine" (Rothman, 1991: p. 221). In the context of neonatal crises management, the challenges to authority were circumscribed narrowly.

The third example is a consideration of the early development of national bioethics commissions, whose work "both profited from and contributed to the development of bioethics."¹³ It suggests how bioethics won cultural authority and institutionalization by mediating between challenges to biomedical authority and power, on the one hand, and the effort to shore up biomedical autonomy by scientists and physicians, on the other.

The national bioethics commissions have been characterized as being a part of transformational processes. As David Rothman relates, "As late as 1966, physicians had a monopoly over medical ethics; less than a decade later, lay people, dominating a national commission, were setting the ethical standards. Medical decision making had become everybody's business" (Rothman, 1991: p. 168 and p. 175, respectively). He underscores the impressive, 'unbending opposition' to the proposal of a commission, relating that many physicians and investigators found the idea of a panel meddlesome and dismaying: "leaders in medicine fought doggedly to maintain their authority over all medical matters;" and, "the geneticists and psychiatrists who testified (at the legislative hearings) were as antagonistic to the idea of a commission as the surgeons" (Rothman, 1991: p. 169).

Ultimately, the legislation establishing the first federal commission, the 1974 National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research, created a weaker body than the one originally put forward. The 1968 proposal had wanted to establish a National Commission on Health Science and Society. Instead, the

commission would be concerned not with health science and society issues but only with human experimentation (although a subsequent commission expanded its topical ambit). It could make recommendations to the Department of Health, Education, and Welfare but it had no enforcement power, and it would last only 4 years. There would be no permanent national human investigation board.

For Jay Katz, law professor and expert on the social and legal ramifications of human experimentation, the temporariness of a commission on human experimentation was the result of 'subterfuge.' He opined later that the reason a permanent commission was not established "may have been the Senate's reluctance to expose to public view the value conflicts inherent in the conduct of research. Had the Senate seriously debated the bill, it would have been forced to consider when, if ever, inadequately informed subjects can serve as a means to society's and science's ends. I believed then as I do now, that the rejection of an NHIB (National Human Investigation Board) was not just a mistake but a subterfuge to avoid giving greater visibility to the decisions made in the conduct of human experimentation" (cited in Fox and Swazey 2008: p. 50). Law professor and bioethicist, George Annas has also reflected critically. The commission, he felt, had endorsed the status quo. It failed to examine three premises: research is good, experimentation is almost never harmful, and research-dominated independent review boards can adequately protect research subjects (Jonsen, 1998: p. 106).

Annas' critique sheds an interpretive light on one of the commission's unique tasks, one that was highly consequential to bioethics' development and its eventual managerial orientation. Commissioners were instructed to "...identify the ethical principles which should underlie the conduct of biomedical and behavioral research with human subjects and develop guidelines that should be followed in such research" (Jonsen, 1998: p. 102). This was an authorization to facilitate means rather than an invitation to assess the morality of ends. The project resulted in the 1976 *Belmont Report*. The report concluded that there were three universal principles relevant to human experimentation: respect for persons, beneficence, and justice.¹⁴ These principles, in turn, required implementation of informed consent, risk-benefit assessment, and the just selection of research subjects (Jonsen, 1998: pp. 103-104). This new type of analysis, 'principlism,' did not function to dig deep into the concerns that first fired bioethical imagination, e.g., whether and how a variety of biomedical technologies may be threatening values undergirding the uniqueness of human life or the nature of the human species. Principlism (begun by Georgetown bioethicists) becomes bioethics' managerial toolbox, one carried beyond its first use in the context of human experimentation. But its initial institutionalization was as the product of a legislative mandate for the creation of a mediated process. It was a method settled upon after years of contention between those challenging the morality of research agendas and medical practices and those seeking to bolster scientific and medical authority.

¹³ Jonsen, 1998: p. 90. See Jonsen's Chapter 4 on "Commissioning Bioethics: The Government in Bioethics" 1974-1983; Rothman's (1991): Chapter 9, "Commissioning Ethics"; and Fox and Swazey's (2008): pp. 44-52, "Bioethics Goes to Washington."

¹⁴ Tom Beauchamp and James Childress, in their widely used text, *Principles of Biomedical Ethics*, break down these principles into four: autonomy, beneficence, nonmaleficence, and justice. cf Evans, 2012: p. 46.

In his analysis of public debate over HGE from the 1950s to the mid-1990s, sociologist John Evans evaluated the role of commissions in the ‘thinning’ of that debate. When theologians and others challenged geneticists who were seeking to normalize HGE, scientists responded by advocating “the creation of government advisory committees that would ease calls for setting the ends of HGE research through congressional action” (Evans, 2002: p. 7). Evans demonstrates how “the locus of the HGE debate was purposefully shifted away from the public to the bureaucratic state” where, “one choice was impossible – the decision *not to engage* in any HGE italics in original, Evans, 2002: p. 4 and p. 5, respectively). “Each particular community – be it Roman Catholic, feminists, or African-Americans – would still use the thick debate among themselves, but would translate their thick debate to the thin shared language for use in public.¹⁵”

These historical considerations, one institutional, one clinical, and one governmental, point to a variety of open historical questions such as: the role of funding constraints in shaping public oversight, the demand for outside moral assistance that came from within medical ambits, the strategic value of guideline creation in delegitimizing the moral analysis of certain ends, etc. What the three considerations bear in common, however, is a tale of how the expansion of biomedical decision-making arenas to include ‘outside’ (bioethical) input, also involved a narrowing of one kind or another, a narrowing that always facilitated or was facilitated by adherence to principlist methods and solutions.¹⁶

With the ascendancy of principlism, the scope of discussion that birthed bioethics concerning what goals the new technologies should or should not serve, constricts. Theological critique, in particular, which had been highly influential in the earliest days of concern, (what might be called, ‘proto-bioethics,’) was marginalized.¹⁷ “One of my toughest problems during the Hasting’s Center’s first twenty years,” Dan Callahan reflected, “was persuading the philosophers to sit down with the theologians and to take them seriously. The secular philosophers could not give a damn for what the theologians were saying and were even scornful” (quoted in Jonsen, 1998: pp. 83–84; see also, Callahan, 2012: pp. 15ff).

Critique from Within and Without

By the 1990s, bioethicists were registering concern over the limitations of principlism. For Callahan, for example, principles were necessary but, “...should not be understood as moral trump cards” (Fox and Swazey, 2008: p. 170. See also, Belkin, 2004: p. 374; Callahan, 2012). Sociologists, some of whom were part of the founding generation of bioethics, found themselves on the margins of bioethics as the field’s discourse and analytical

purview, narrowed (cf Fox and Swazey, 2008; Bosk, 2008b: pp. 226–249). Sociologist Charles Bosk’s succinct ‘scold’ for this marginalization conveys what, for a number of sociologists, principlism has cost ethical analysis: “It has inhibited...any genuine appreciation of the logic and wisdom of cultural and ethical systems that place less value on the individual than does American civil religion.¹⁸” The attribution of American bioethics’ universality, naturalness, and objectivity – what gives it its ‘compulsive force’ – is, for Bosk, culture bound (Bosk, 2008b: p. 231). Eventually, sociologists plead openly to let sociology ‘help’ bioethics as evidenced, in part, with article titles, e.g., “How Can We Help? From ‘Sociology in’ to ‘Sociology of Bioethics,’” and, “How Sociology Can Save Bioethics...Maybe.¹⁹” Adam Hedgcock’s 2004 article offered bioethicists a ‘critical bioethics’ road map for engaging empiricism in ethical analysis, encouraging them “...to challenge theories using evidence, to be reflexive and to be skeptical about the claims of other bioethicists, scientists and clinicians” (Adam Hedgcock, 2004: p. 120. See also, Borry et al., 2005; Twine, 2005).

Some suggest that even critical empirical approaches must push more critically (see, for example, Murray and Holmes, 2013). Stuart Murray and Dave Holmes, for example, challenge principlism’s ‘cognitive conceit’ that “the conventional subject of bioethics is presumed to be a stable and coherent self, sovereign in its ethical judgements.... [...suggesting] that to live is...no different than to know...” (Murray and Holmes, 2009: p. 3). “We need only reflect on the body in illness and pain,” they continue, “to understand that the rational and coherent subject is a conventional fiction...Any ‘autonomous’ decision takes place between the patient and a vast healthcare complex in the face of which the patient can hardly be said to be ‘rational’ or ‘free’” (Murray and Holmes, 2009: p. 4. See also, Murray and Holmes, 2013).

Feminist bioethics, underway in earnest by the 1980s and a discernable academic concentration by the 1990s, began with a challenge to the “standing assumption that men are the norm for human beings” (Nelson, 2000; Donchin, 2004). From an early concern with women’s health and reproductive issues, the now sprawling field radiates robust topical and theoretical spokes from critique of the mainstream center to the critical margins (Scully et al., 2010).²⁰ Anne Donchin’s concise summary of the field’s common goals serves to underscore its critical edge: integrate race, class, ethnicity, and gender into bioethical theory; reexamine bioethical principles; include the ‘standpoints of those who are socially marginalized’ (Donchin, 2004, ‘Feminist Bioethics,’ p. 5). Feminists, for example, have tied cultural attitudes toward women’s bodies as well as the pressure to use prenatal techniques to produce ‘perfect’ children, to the stigma of

¹⁵ Evans, 2002: p. 5; see also, Brody, 2009: pp. 225–227, for a discussion of the ‘laundering’ aspect of the commission ‘consensus’ method of deliberation.

¹⁶ Rothman’s larger framing supports the view that the period from 1966 to 1976 brought unprecedented challenges to medical authority, a concern of his book being “[h]ow did it happen that physicians, who had once ruled uncontested over their domain, came to confront committees, forms, general principles, and active patients?” Rothman, 1991: p. 4.

¹⁷ On the decline of theology in bioethics, see Evans, 2002, 2012a,b.

¹⁸ Bosk, 2008b: p. 234. See also, Fox and Swazey, 2008, Chapter 6: “Thinking Socially and Culturally in Bioethics,” for extended discussion.

¹⁹ Respectively: De Vries (2003), Lopez (2004). For discussions or research relevant to sociology and bioethics, see for example, De Vries and Conrad (1998), Hoffmaster (2001), Fox and Swazey (2008). For discussions or research relevant to history and bioethics, see, for example, Rosenberg (1999), Brandt (2000), Belkin and Brandt (2001), Baker (2002), Stevens (2003), Short (2003), Belkin (2004), Wilson (2011), Emmerich (2011), and McWhirter (2012).

²⁰ See ‘Introduction’ for concise discussion of the challenge and necessity for feminist bioethics to “...continually renegotiate its engagement with the mainstream” (p. 7).

disability. (Donchin, 2004: pp. 6–7. See also, Parens and Asch, 2000; Scully et al., 2010; Mahowald, 2010).

Despite criticism from both within and without the profession,²¹ principlism became the bioethicists' stock in trade as institutional review boards, hospital ethics committees, and clinical ethics, incipient in the 1960s and 1970s, became more deeply institutionalized throughout the 1980s and 1990s.²² As bioethicist Carl Elliot has observed, while early bioethics was unaffiliated with medical institutions, the field became "more tightly incorporated within the structure of medicine itself," as it gained legitimacy (Elliot, 2010: p. 148). Elliot has underscored troublesome aspects of this institutionalization unrelated to principlism per se, namely, the conflict of interests bioethicists operate under when they accept payment from pharmaceutical and biotechnological industries: "Some of it goes straight to individuals, in the form of consulting fees, contracts, honoraria, and salaries. Some of it – such as gifts to bioethics centers – is less direct. Many corporations are putting bioethicists on their scientific advisory boards or setting up special bioethics panels to provide in-house advice" (Elliot, 2001, 2010).²³

Contemporary Challenges, Continuing Critique

By the turn of the twenty-first century the 'culture wars,' operational in America's sociopolitical culture more broadly since the late 1970s, came to affect bioethics more specifically, working to amplify underlying incipient tensions between liberal and conservative impulses within the profession and diminish claims made for principlism's universal appeal. Bioethicist Ruth Macklin has taken issue with the terms 'liberal' and 'conservative' for the way they, "lump together...an array of widely divergent and often nuanced positions" (Macklin, 2006: p. 35). Even so, disagreements over human genetic modification and especially on issues pertaining to the beginning or end of life (e.g., research involving embryos, at one end, or when to terminate life support, at the other) grew so vituperative that some bioethicists feared the field would implode.²⁴ President Bush's decision to limit federal funding of embryonic stem cell research to cell lines created from embryos already destroyed, his 2001 appointment of conservative bioethicist Leon Kass to Chair the President's Council on Bioethics, and that Council's recommendation of a 4-year moratorium on federal funding of research cloning, led to particularly acute contention. When two dissenters to the Council's cloning report were dismissed, a number of mainstream bioethicists viewed the termination as conservative/neo-conservative stratagem (see, for example, Charo, 2004; Fox and Swazey, 2008: pp. 285–316).

The overt political nature of the disagreements also compromised the authority and effectiveness of federal bioethical policy making. Scientists unable to secure federal bioethical sanction or adequate funding for embryonic stem cell research took their case to the states. California, for example, provided researchers with a more agreeable political environment. Their efforts, which resulted in the passage of that state's 2004 Proposition 71 and its \$3 billion authorization to fund the California Institute of Regenerative Medicine did not require federal bioethical imprimatur.²⁵

In 2005, bioethicist Jonathan Moreno related his distress over what he characterized as a 'crisis of identity' for bioethics, one with the potential to threaten the survival of bioethics, as it had been known. That bioethics, "...developed the consensus philosophy and social role it has largely assumed since the 1970s: Keep a close eye on scientific innovation for its societal implications, apply the brakes now and then as needed through regulations or guidelines or just the glare of public discussion, and let the bioethicists be the ones to analyze how all this is going. Call it the Great Bioethics Compromise" (Moreno, 2005: p. 14). With this 'compromise' in jeopardy, some bioethicists have called for the remedy a 'progressive' bioethics might offer. A progressive bioethics, inspired by the larger progressive movement embodied in such groups as the American Constitution Society and Center for American Progress and drawing on 'leftist and moderate' ideas and people, would 'return' to social justice questions and its practitioners would take a more activist role.²⁶

Sociologist John Evan's unique solution to the bioethics' crisis is for bioethicists to abandon their work in the realm of what he refers to as 'cultural bioethics,' i.e., they should discontinue, "...trying to convince the ordinary citizens (sic) of the proper ethical course of action concerning a medical or scientific technology or practice" (Evans, 2012a: p. xxxiii). An empirically informed, 'modified version' of principlism remains advisable for bioethical participation in health care ethics consultation, research bioethics, and public policy bioethics (i.e., proposing ethical courses of action for scientists and physicians, such as federal commission work). But, bioethicists should not agree to media interviews, write tracts for public consumption, communicate through social movement organizations, etc. Attempts to discredit bioethical commissions or bioethicists more generally would then fail, as Evans sees it, because public policy bioethics debates would have publicly determined the values that bioethicists forward to commissions on behalf of citizens (Evans, 2012a: p. 159).

Recently, the policy-making function of federal commissions has faced challenge from environmental groups and their organizational allies, which, though less high profile than the tensions giving rise to bioethics' 'crisis,' is noteworthy. In 2010, the Presidential Commission for the Study of Bioethical Issues gave a green light to 'synthetic biology,' a field of research that includes creating novel organisms by manipulating synthesized DNA not found in nature. After

²¹ see Fox and Swazey, 2008, pp. 156–157, for a discussion of critical views on principlism held by bioethicists

²² See Brandt (2000), for instructive list of questions requiring scholarly assessment of bioethics in medical and research areas.

²³ The globalization of clinical trials has brought additional concerns (See, for example, Petrayna, 2009).

²⁴ Callahan recently reflected that, "if there are signs of the larger society's culture wars in bioethics, the field...has remained remarkably friendly and irenic" (Callahan, 2012: p. 19)

²⁵ Indeed, that campaign received scant attention from bioethicists whatsoever. See Stevens (2007).

²⁶ Moreno and Berger, 2012: p. xix; pp. 20–21. Whether a progressive bioethics will expand its evolving ambit to include a 'thick' consideration of ends, however, remains to be seen (See Evans, 2012b: pp. 119–141).

hearing testimony against allowing the synthetic biology industry to self-regulate, some critics were invited to offer comment on the Commission's (unenforceable) recommendations for self-regulation. While they did offer comment, they did not do so as part of the elite bioethics commission process.²⁷ Instead, they presented commissioners with an open letter of disapproval signed by 58 civil society organizations in 22 countries.²⁸ In 2012, Friends of the Earth, ETC Group, and International Center for Technology Assessment promulgated, "Principles for the Oversight of Synthetic Biology" that, among other suggestions, called for a moratorium on the release and commercial use of synthetic organisms and their products. The document was endorsed by 111 civil society organizations from around the globe.²⁹

Conclusion

The long arc of US history and the American tradition of ambivalence toward 'progress' suggest that bioethics' unique historic significance is not that the impulses giving rise to it arose in response to biotechnological developments. Rather, it is that those impulses instead of dissipating were institutionalized. Bioethics came to serve as methodology for the social processing of biotechnological ramifications perceived as potentially troubling. The political culture that selected bioethics for that processing, a culture in which (bio)technological development is deeply embedded, remains, and with it remains its need for the function bioethics serves. Hastings Center cofounder, Willard Gaylin's 1979 reflection conveys something of the nature of that function: "We don't see ourselves resolving moral dilemmas. But we want to ensure that when an issue reaches the public marketplace, it won't be greeted with hysteria" (quoted in Stevens, 2000: pp. 70–71).³⁰ The enduring demand for this function brings into focus questions of continuing historical interest: will bioethical expertise be devalued as a result of bioethicists participating as partisans in broader political-cultural disputes rather than as neutral arbiters of ethical quandaries; if so, how will the larger society negotiate that devaluation; and will that negotiation be transformative of society itself?

See also: Animal Research Ethics; Bioethics, Clinical; Disability and Bioethics; Ethical Issues in Behavioral Healthcare; Ethics of Issues and Stem Cell Research: The Unresolved Issues; Ethics of Placebos; Feminism and Bioethics; Genetic Ethics; Health Care Rationing; Law and Bioethics; Pharmacy Ethics; Philosophy of Biology; Public Health Ethics; Reproductive Technologies, Assisted; The Ethics of End of Life; The Patient–Doctor Relationship.

²⁷ Quoting from the *Penguin Dictionary of Sociology*, John Evans uses the term 'elite' to mean "a minority group which has power or influence over others, and is recognized as being in some way superior." (Evans, 2012b: p. 140; for an analysis of these categories, see Evans, 2012: pp. xxvii–xxxv.)

²⁸ [Open Letter to the President's Commission, 16 December 2010](#)

²⁹ [Principles for the Oversight of Synthetic Biology, 2012](#)

³⁰ See also, Caplan (2005) for a discussion that implicates bioethics' politicization as a function of its power brokering capacity.

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