



The Penn Center Guide to Bioethics

Vardit Ravitsky

Autumn Fiester

Arthur L. Caplan

Editors

The logo for the Penn Center for Bioethics, featuring the University of Pennsylvania crest to the left of the text "Penn" in a large blue serif font, with "CENTER for BIOETHICS" in a smaller red sans-serif font below it.

Penn
CENTER for BIOETHICS

The Penn Center Guide to Bioethics

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Preface

AUTUMN FIESTER

The *Penn Center Guide to Bioethics* is a collection that represents the “Penn way” of doing bioethics. The University of Pennsylvania’s Center for Bioethics takes a distinct approach to the field of bioethics, reflected in the issues we address, the integration of the empirical and the normative, the educational programs we offer, and the level of engagement we have with both the public and the stakeholders in the controversies of bioethics.

The Penn Center for Bioethics is recognized as one of the global leaders in the field of bioethics. Since its founding in 1994, under the leadership of Arthur Caplan, the Penn Center has sought to tackle the traditional issues of bioethics as well as the emerging issues, helping to shape the academic and public discourse on the challenging questions generated by new technologies and medical advances.

The field of bioethics came into being decades ago because of ethical quandaries such as abortion, withdrawal of life support, and human research subjects protection, and the Penn Center includes these important issues in its research agenda. However, as both the life and medical sciences have experienced unprecedented growth and progress, a host of new ethical issues have emerged, and the Penn Center seeks to navigate these uncharted ethical terrains as well.

The Penn Center closely follows the latest technical and medical advances to map out and help resolve the issues raised by cutting-edge research. The Penn Center has an eye out for the ethical quandaries that are on the horizon so that public debate can have a head start in grappling with emerging ethical issues involved in areas such as neuroethics,

biobanking, genetic screening, nanoethics, bioterrorism, and animal biotechnology—to name just a few.

The Penn Center is known for innovative, multidisciplinary scholarship that draws on the expertise of disciplines as diverse as social science, philosophy, theology, law, public policy, business, and clinical training. The Penn Center was one of the first bioethics centers to emphasize and produce empiricized bioethics, using the methods and approaches of empirical inquiry to shed light on bioethical issues. The *Penn Guide* effectively reveals this diversity in discipline and method.

The *Penn Guide* also reflects the center's pioneering approach of integrating bioethics scholarship with practical application, not merely in clinical medicine but in the realms of public policy, public debate, and industry. The Penn Center has always viewed its mission as the marriage of theory and practice: the center is not an armchair institution, generating publications by scholars to be read merely by other scholars. That approach has its place in the academy. But the Penn Center strives to play an active role in policy, education, consultation, and public debate because bioethics is not just academic—bioethical dilemmas confront all of us, at one time or another, in either our personal or professional lives.

The Penn Center fosters public discourse, from our unique High School Bioethics Program to our consultations with medical institutes, advocacy organizations, and industry, as well as the many public lectures Penn faculty and fellows deliver. The Penn Center intentionally uses print, electronic, and other broadcast media to put bioethical issues on the public's agenda.

This commitment to assisting individuals who are on the frontlines of bioethics can be seen in our renowned Master of Bioethics Program, founded in 1997. The Penn Master of Bioethics Program is designed for professionals who work in areas that put them at the center of bioethical conflict. Our students come from the fields of medicine, nursing, veterinary medicine, dentistry, law, public health, the pharmaceutical and biotech industries, clergy, and government. Our mission is to give professionals the tools they need to address the bioethical issues that arise in their workplace.

The *Penn Guide* mirrors the style and commitment of the Penn Center for Bioethics, and we hope it will promote these important debates.

Introduction

VARDIT RAVITSKY

Although it is coming of age, bioethics is still a relatively young field of inquiry. It constantly searches for appropriate methodologies and conceptual tools and frequently embraces complex multidisciplinary approaches. It is exciting and challenging, embedded in cultural and political contexts and always in touch with cutting-edge scientific progress. Bioethicists think, write, and advise, contributing perspectives that benefit patients, research participants, communities, professionals, policy makers, and the public at large.

The Center for Bioethics at the University of Pennsylvania has been a leading hub in American bioethics for over a decade. *The Penn Center Guide to Bioethics* features the diverse bioethics expertise of scholars around the university, as well as the contributions of those who have been associated with the center in the past years.

Contributors to this volume were asked to provide an overview of their area of study that would be accessible for professionals and lay readers alike. At the same time, the editors invited authors to speak in their own voices and express their own perceptions of how their field has evolved, where it stands today, and where they believe it is heading. We encouraged them to maintain a distinctive style that reflects not only their own disciplinary background, but also their unique personal viewpoints. Rather than adopting a *neutral* stance, chapters are intended to engage the reader by provoking thought and critical reaction.

Many of the contributors are senior researchers who have established themselves as academic authorities in their respective fields. Others are more junior bioethicists who show great promise to become

the leading scholars of the future, representing the next generation that will shape bioethics in the coming years.

Each chapter offers some historical background and an overview of the relevant issues, but also a focus on certain arguments—of the authors' choosing—within the general topic. The *Penn Guide* allows any reader, coming from any background, to appreciate the context and the scope of each subject while obtaining a more nuanced and sophisticated analysis of some specific aspects.

These diverse voices complement each other at times, and diverge at others. The interplay of perspectives offers the reader a rounded view of the vibrant world of bioethics as it unfolds. The *Penn Guide* thus captures a snapshot of present-day bioethics through the lens of the research carried out in a leading university and by those associated with it. It does not aspire to be a comprehensive collection representing every aspect of the field. Considering the broad scope of bioethics today, this would have been impossible. Rather, the *Penn Guide* is meant to provide a rich and integrated overview, allowing the reader to appreciate classical topics as well as a sample of recent developments.

In this volume, you will find:

- ◊ both classical topics in clinical bioethics—such as confidentiality, advance directives, and medical futility—and emerging issues, such as nonprofessional caregiving;
- ◊ a focus on long established practices, such as nursing, as well as an exploration of new ones, such as mediation;
- ◊ elaboration of well-established areas in research ethics—such as informed consent and placebo control trials—as well as new areas, such as innovative surgery or how race, gender, and age play a role in inclusion and exclusion of participants in clinical trials;
- ◊ reflections on centuries-old issues, such as eugenics, but also new ones, such as privacy of thought in the age of brain imaging;
- ◊ a discussion of established technologies, such as prenatal genetic testing and in vitro fertilization, and more recent ones, such as pre-implantation genetic diagnosis and the cloning of animals; and
- ◊ an examination of familiar bioethical topics in public health, such as quarantine and vaccination, but also emerging issues in this field, such as national security or nonprofit organizations.

The outcome is a book that offers a rich and colorful tapestry of current viewpoints, set in a myriad of tones and styles, mirroring the diversity of a field in which new challenges emerge daily.

* * *

A brief look at the history and evolution of bioethics sheds light on the *Penn Guide* and what it has to offer. Bioethics has come a long

way since its inception in the 1960s. Born in response to violations of human rights in biomedical research, its initial focus was the protection of individuals. Indeed, one of its most successful endeavors has been the establishment of principles and mechanisms for protecting research subjects, particularly by developing the concept of *informed consent*. The core ethical principle underlying this focus has been *autonomy*, the right of every individual to self-determination as a patient and as a subject within health care and research systems that were growing in size and complexity.

Bioethics' focus on autonomy also meant that it pushed toward a shift in the physician-patient relationship, from a paternalistic model to a more contractual one. It promoted the empowerment of patients and obliged professionals to acknowledge patients' rights to decide for themselves what is in their best interest, including their right to refuse treatment and to make end-of-life decisions.

For the first couple of decades, bioethicists' intellectual energy was thus invested mostly in the realm of *negative rights*, rights to be protected from unwarranted intrusion and to be left alone to exercise one's autonomy. One important aspect of the evolution of bioethics is the shifting of its attention toward *positive rights*, rights that impose obligations on others not just to refrain from action, but rather to provide certain benefits, such as the right to health care or the right to be included in research. Such rights create obligations on the part of society, and their implementation can be costly. They therefore entail an ethical discourse that goes far beyond the focus on autonomy, to include considerations such as distributive justice, allocation of resources, and priority setting.

As bioethics evolved, these considerations began to take center stage, and a growing number of bioethicists started to tackle complex and politically charged issues such as the right to health care and strategies for rationing. Their work reveals the progress that bioethics has been making in realizing that the protection of autonomy is not sufficient when many Americans, as free and informed as they may be, have no access to health care and are denied benefits that privileged individuals take for granted. Furthermore, this work expands the scope of bioethical discourse from the traditional focus on Western democracies to a global perspective. It embraces a discussion of the needs of the poor in developing countries and does not shy away from advocacy.

This shift is evident in the content of the *Penn Guide*. Some chapters structure their ethical discussion around principles such as autonomy, while others expand the discussion to include these more recent debates, such as access to health care, fair pricing of medicines for the poor, and the rights of minorities to be included in research.

A second aspect of the evolution of bioethics is reflected in the growing attention dedicated not just to individuals but also to the

interests and perspectives of communities, cultures, and societies. For example, the rapidly growing area of *public health ethics* is focused on the tension—and the appropriate balance—between respecting the rights of individuals and the interests of the public. When these two perspectives clash, intriguing bioethical challenges emerge. Bioethicists have begun to describe and analyze these issues, and to propose ethical frameworks for addressing them.

Some of the *Penn Guide's* chapters reflect this development. Authors outline possible frameworks for public health ethics, discuss a *code of ethics for public health*, and even demonstrate how bioethical analysis plays out in specific cases encountered by practitioners on the ground. They explain when practices such as isolation and quarantine, which limit the freedom of individuals, can be ethically justified as a public health measure. They also explore diverse issues such as mandating vaccination of health care workers, which is crucial for the protection of vulnerable patient populations but may violate the rights of individual workers, or tobacco taxes that are designed to discourage smokers in order to promote public health but have an adverse economic impact on the poor.

Moreover, chapters in various sections of the *Penn Guide* address bioethical concerns on a social, not just an individual, level. Genetic research, for example, benefits individuals in many ways, and its ethical implications for individuals have been discussed extensively in the bioethical literature. However, genetic research gradually reveals information about genetic differences between populations that has the potential to harm certain populations by strengthening misconceptions about race. This raises questions about the *social* consequences of conducting such research and whether it should be pursued in the first place. The *Penn Guide* explores the possible expansion of research ethics from its classical concern for the protection of *individuals* to include questions about what type of research can benefit or harm *society* and whether it should be supported or discouraged.

A third aspect of the evolution of bioethics is related to the ethical challenges raised by new technologies. Bioethics initially focused on the ethical implications of new technologies such as mechanical ventilation, artificial nutrition and hydration, and organ transplantation at the end of life, as well as in vitro fertilization and prenatal genetic testing in the beginning of life. Bioethics has traditionally applied theories and principles, developing new conceptual tools and methodologies that were necessary for the analysis of such issues.

As bioethics evolves into a more mature discipline, the ethical, legal, and social implications of biotechnology are becoming an even greater focus of its work. Bioethicists debate among themselves about the need to develop new specialized subdisciplines to address new types

of technologies. For example, advances in brain imaging raise new and fascinating ethical questions, but do we need new conceptual tools to address them? Do we need *neuroethics*, *genethics*, and *nanoethics* as offshoots of *bioethics*? The *Penn Guide* tackles these issues and offers the unique perspectives of leading scholars in the relevant fields.

Finally, the evolution of bioethics has brought the field to a point in which it requires specific training and expertise and allows for a spectrum of possible careers, from traditional academic positions all the way to consultant positions for government or industry. This development brought to the forefront the need for bioethicists to be accountable and aware of their own potential biases and conflicts of interest. Rather than relying solely on personal integrity, bioethics as a discipline is now conscious of the need for a more formalized mechanism, a *code of ethics for bioethics*. This recent debate is depicted in a few chapters of the *Penn Guide* that allow the reader a glimpse into this internal discourse that will shape the future of the discipline.

* * *

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Part I

Bioethics: Birth, Evolution, and Context

The Birth and Evolution of Bioethics

ARTHUR L. CAPLAN

THE ORIGINS OF bioethics are hard to pinpoint but not, as is often the case in trying to pinpoint when something began, as a result of the obscuring effects of the mists of time. Bioethics is still very young—the mist is not all that dense. Indeed, bioethics is so young that some of those present at its birth are still with us.

A few of the founders have taken pen in hand and given us their thoughts about the field's origins (Jonsen, 1998; Macklin, 1987). Others from outside the field have offered their analysis of bioethics' origins (Fox & Swazey, 2008; Rothman, 1991; Stevens, 2000). Still, there is no obvious consensus in these works about when bioethics began. The battle over the field's origins is not so much a fight about who did what to get things going and when, but rather whether one dates the origins to a particular institution, scandal, or issue.

THE ORIGINS OF BIOETHICS

SOME DATE THE field to the founding of the first think tank devoted to the subject, the Hastings Center. The center began, somewhat inauspiciously in terms of long-term financial security, in the Hastings-on-Hudson, New York, home of the Columbia University

psychiatrist Willard Gaylin in partnership with Gaylin's neighbor, the philosophically trained writer and editor Daniel Callahan, in 1969.

Those who doubt any claim about the existence of anything until it is confirmed lean toward 1971 as the date of origin for bioethics. In that year, Hastings was joined by the Joseph and Rose Kennedy Institute of Ethics at Georgetown University. Unlike the Hastings Center, the Kennedy Institute was explicitly organized around religious perspectives on bioethical issues. Hastings tended to operate with groups of scholars from different disciplines addressing problems. Kennedy followed a more traditional model of individuals pursuing their particular scholarly projects and interests.

There are those who see the field as beginning much earlier. Some point to the creation of the renal dialysis so-called life and death selection committee in Seattle, Washington in 1961 (Jonsen, 1998). This committee commands attention because it was one of the first efforts to ration access to a life-preserving therapy by a committee of physicians and lay persons explicitly charged with making ethical rather than purely medical decisions. But, while the committee was a watershed in how America thought about distributing scarce resources, it did not really give birth to a field of scholarship and inquiry.

A few go back to the trial of Nazi doctors for their role in horrific experiments in the concentration camps (Annas, 2005). The Nuremberg Code, which resulted from this trial and subsequently was modified into what became the World Medical Association's 1964 Declaration of Helsinki, is seen as a key foundational document that grounded bioethics in a human rights framework.

Still others see bioethics as having its birth date in the Tuskegee scandal, when the whistle was first blown in 1971 on a study of the impact of syphilis on poor Black men in rural Alabama that had begun in 1932. An effective treatment for syphilis, penicillin, was well-established and widely available by the late 1940s, but the study continued for 30 more years, fueled by a powerful current of racism until the whole sordid tale was presented to Congress at a series of hearings held by a young Senator Edward Kennedy in 1973.

And a few see bioethics as having its roots far back in the medical ethics thinking done in earlier centuries by such giants of the philosophy of medicine as Robert Koch, Claude Bernard, William Osler, and even Maimonides. However, the work of these men is better understood as contributing to the creation of the ethics of the medical profession rather than the contemporary field of bioethics. The norms that ought to guide medicine as expressed in professional medical ethics are neither sufficient nor equivalent to the field of bioethics, which examines the problems and dilemmas arising from the health and life sciences for patients and the public as well as for professionals.

Bioethics, in my view, began in response to scandal and uncertainty. As much as the field should have begun in the aftermath of the Holocaust and the prominent role played by medicine and science in both horrific mass murder and awful human experimentation, it did not (Caplan, 2005a). Human rights thinking may have begun then (Annas, 2005), but bioethics as a field did not. Few Americans wrote about ethical problems in medicine or medical research in the 1950s and 1960s. The Nuremberg Code was seen as requisite for Nazis and other ideological lunatics, not for researchers working in the United States, Britain, or Western Europe.

Scandal surrounding the abuse of subjects in various research studies—as exemplified in the classic paper of Henry Beecher, MD (Beecher, 1966) and the Tuskegee experiment—made it clear that American researchers were more than capable of treating subjects in unethical ways. Emerging technologies such as ventilators, heart-lung machines, transplants, and kidney dialysis raised in the late 1960s new and profound questions about who should be granted access to expensive treatments and when they could be withheld, withdrawn, or denied (Caplan, 1993). Such technologies created uncertainty and posed new challenges to clinicians. This combination of scandals in research and uncertainty about managing new and expensive therapies combined to set the stage for the birth of bioethics. The Hastings Center and the Kennedy Institute of Ethics were conceived in the midst of scandal and flourished in an environment of a medical profession eager for help.

THE DEVELOPMENT OF BIOETHICS

BIOETHICS BEGAN AS a field, not a discipline. No single theory or outlook defined bioethics as would be the case for most disciplines. All voices, creeds, and types of expertise were welcome to engage in formulating answers to questions of research ethics and managing therapies. It was problems that held inquiries together and created the field of bioethics, rather than a particular mode of analysis, a set of theoretical views, or a set of disciplinary tools. But that quickly changed.

It proved very difficult to do bioethics in public in anything approximating a religious voice. While theologians were drawn to bioethics in the 1970s in large numbers and from many creeds, it quickly became clear that to command the attention of scientists and physicians, as well as policy-makers, a more secular language was required. Philosophy, emerging out of decades of mainly futile wrangling about meta-ethical issues, was more than happy to oblige, and medicine was happy to utilize its science-friendly worldview (Toulmin, 1973).

As bioethics began to grow, it was philosophical analysis and language that became the primary spoken tongue of the field. This period lasted about 10 years. At that time, in the 1980s, both lawyers and physicians began to assert more authority over bioethical discourse. As bioethics began to move away from its peripheral status outside American universities to centers and programs within them, academic medical centers became the home of choice. The culture of academic medicine—grant-driven, pragmatic, publication-oriented, and clinically focused—came to reshape bioethics from a field where people talked philosophy into a discipline where communicating with physicians was essential.

Since that time bioethics has rapidly evolved to become a discipline. Noninitiates who lack formal training in bioethics are not as welcome. Having a graduate degree of some sort in bioethics has become a bit of a credentialing requirement for someone to be taken seriously in matters bioethical. The pressure to conform to the mandates and norms of academic medicine has grown stronger, with much talk of the impact factor of journals, empirical and quantitative studies of bioethical issues, and research ethics compliance. There is even growing attention to the so-called ethics of bioethics and to potential conflicts of interest bioethicists may find themselves struggling with, which parallels the larger crisis of confidence in the integrity of the medical profession.

The public, media, and public officials in the economically developed world have grown somewhat accustomed to showing some deference to bioethical practitioners on a wide range of subjects, even if there is still discomfort about the concept of nonreligious ethical experts or, in some more secular quarters, any ethics expert, no matter how secular they may sound. Commissions and blue ribbon panels are now common. And bioethics has become international with programs, centers, and practitioners scattered around the globe.

CONCLUSION

HAVING GROWN INTO a feisty young adult, bioethics is now both eager to work with powerful social institutions and governments (Caplan, 2005b) and at the same time is more than willing to get down on the ground and wrestle over its appropriate focus, techniques, methods, and value-stance. Born in troubled times, bioethics continues to be a cultural flashpoint where disagreements run deep, the stakes continue to be high, and the voices and sources of authority are diverse.

What is uncertain is whether the discipline of bioethics, which now has its own canon, textbooks, encyclopedias, legal landmarks, legislative

triumphs, associations, degree programs, tenured positions, chairs, handbooks, and, yes, guides, will continue to enmesh itself with academic medicine or take a turn back toward the humanities, law, or public policy. It is also unclear whether pressures to cover cost will lead to the emergence of professional requirements including licensure for those working in clinical settings and stronger efforts to form consulting and educational programs in the research area. It is clear that what began as a response to American research scandals and an explosion of technology into American medicine has grown into a far different entity with entirely new challenges, pressures and opportunities.

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The Ethics of Bioethics

ROBERT BAKER

UNTIL RECENTLY, FEW bioethicists took the ethics of bioethics seriously—if they gave it any thought at all.¹ Over the last decade, North American bioethicists—or, at least those who belong to the American Society for Bioethics and Humanities (ASBH) and the Canadian Bioethics Society (CBS)—began to favor a code of ethics for bioethics. A recent survey found ASBH members favoring such a code by a margin of 3.6 to 1 (Baker, Pearlman, Taylor, & Kipnis, 2006, p. 9). This chapter discusses the events that led most American bioethicists to change their view on the need for an ethics for bioethicists.

THE CHARLESTON AND TORONTO INCIDENTS AND THE SOLIPSISTIC CONCEPTION OF BIOETHICS

AMERICAN AND CANADIAN bioethicists' changed attitude toward an ethics of bioethics can be traced to events that unfolded in Charleston, South Carolina and Toronto, Ontario in the late 1990s. Although separated by climate and a national boundary, bioethicists in both cities found their jobs in jeopardy because their employers expected them to act in ways contrary to their own sense of professional propriety. In Toronto, a bioethicist who questioned a decision by a hospital ethics committee wanted to discuss it publicly. Initially, the employing medical center denied the bioethicist permission to

discuss the issue publicly. Although the medical center eventually relented, permitting public discussion of its decision-making, during contract renewal negotiations the bioethicist's supervisor admonished the bioethicist "not to cause problems in the future." In Charleston, the director of a bioethics program was initially denied a promotion after testifying, under subpoena, that the employing medical center's "policy [of incarcerating noncompliant, pregnant, drug-addicted Medicaid patients] fail[ed] to meet the institution's norms or standards that have to do with informed consent... [because] the risk of... arrest and incarceration was not made clear to the patients up front" (American Association of University Professors, 1999; Antommaria, 2004, p. W24).

Both medical centers believed that the bioethicists had failed to act as loyal employees, mindful of the need to speak and act in public forums in ways that protect the interests of the medical centers that employ them. The bioethicists, on the other hand, believed that they had responsibilities that overrode their institutional loyalties. Within 2 years, both bioethicists had sought new employment. The Charleston bioethicist had no choice, since the medical center declined to fund the bioethics program, which was consequently disbanded. The Toronto bioethicist left voluntarily, unable to accept the conditions implicitly demanded by the employing medical center. The underlying problem in both cases lay in the conflicting beliefs about responsibilities of bioethicists.

In 1997, when these incidents began to unfold, no official document endorsed by any bioethics society addressed the issue of the correlative rights and responsibilities of bioethicists and the institutions employing them. A year later, in 1998, the ASBH published a consensus statement, *Core Competencies for Bioethics Consultation* (Society for Health and Human Values—Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, 1998, hereafter, CC), that forthrightly recognized that "conflicts of interest" can arise because "ethics consultants are employed by a health care institution [and their] jobs are dependent on the good will of an institution." CC's approach was to recommend that bioethicists negotiate their prerogatives "proactively with the... institution," and urged institutions to "foster a climate [in which ethicists] can carry out their work with integrity... free of concerns about job security, reprisals, undue political pressure" (CC, 5.2). CC warned, however, that ethicists, "giving advice or otherwise acting against an institution's perceived financial, public relations or other interest may pose potential harms to ethics consultants' personal interests." If a "conflict of interest... puts ethics consultants in the position of shading an opinion to avoid personal risk, [they] should either take the risk or withdraw from the case" (CC, 5.1.4).

CC was thus advising bioethicists to let their conscience be their guide and to quit if their employers required them to act unconscionably. The Charleston and Toronto bioethicists had acted in precisely this way, which apparently was the conventional wisdom of the day. Following this wisdom, however, had left the employing medical centers unapologetically aggrieved and the bioethicists feeling martyred and actually (albeit temporarily) unemployed. By any account, the outcome was unsatisfactory. If the field was to flourish, an alternative was needed.

BREAKING THE SOLIPSISTIC MODEL: THE NEED FOR A COLLABORATIVE ETHICS OF BIOETHICS

THE IDEA OF an ethics of bioethics can appear paradoxical. If one cannot trust ethicists to be ethical, who can one trust? Moreover, if ethicists do not know what is ethical, they lack a *raison d'être*;² if they know what is ethical but cannot be trusted to act ethically, they are self-evidently not in any position to advise others on acting ethically. Thus, if bioethics makes sense as a field, it seems senseless to ponder the ethics of bioethics.

The notion of the ethics of bioethics only appears paradoxical, oxymoronic, or self-evidently redundant if one presupposes that the bioethicist functions in a social vacuum in which only the bioethicist's personal beliefs and willingness to act are relevant.³ The events in Charleston and Toronto, however, demonstrate what should have been obvious: bioethicists do not exist or function in their own solipsistic world, and they typically function in communal environments—hospitals, medical centers, universities—in which they hold others accountable and are held accountable to others.

By the end of the 20th century, bioethics had matured beyond a set of abstruse personal reflections on ethics, biomedicine, and health care to become a multidisciplinary field of practice. No longer the domain of philosophers and theologians and a few sympathetic researchers and clinicians, this multidisciplinary field draws half of its members from clinical areas and the remainder from the humanities/philosophy, the biomedical and social sciences, and religion/theology (Baker et al., 2006, Table 2.3). Pooling their expertise, bioethicists perform an array of administrative, advisory, and educational functions. They consult, evaluate, facilitate, mediate, research, and support people, organizations, and society as they deal with ethical issues in the biological and health related fields. To cite but one example, bioethicists serve on Hospital Ethics Committees, Institutional Animal Care and Use Committees,

Institutional Review Boards or Research Ethics Boards (familiarily referred by their acronyms: HECs, IACUCs, IRBs, and REBs; Baker et al., 2006, Table 2.5). Over two-thirds of bioethicists in the ASBH perform these functions as part of their written job descriptions; one-fifth receive external compensation (Baker et al., 2006, Table 2.6).

Bioethics, as practiced, is not a solipsistic activity; it is not primarily about the sense of propriety that an individual intuitively believes to be correct. Bioethicists are compensated for complex institutional and social activities touching on socially volatile areas. Their practices are subject to assessment and scrutiny by other professionals, by the media, by the public at large, and—as the Charleston and Toronto cases attest—by employers. Fields providing expertise in less volatile areas, from archeologists and beauticians to yacht designers and zoo keepers, offer codes of ethics to provide employers, media, the public, practitioners, and newcomers to their fields with considered statements of their shared understanding of the appropriate ways to practice. Bioethics is unique and, as the Charleston and Toronto cases indicate, uniquely vulnerable because its practices are bereft of the considered collaborative reflection and because its members lack the organizational protections afforded by a code of ethics.

Personal certitude and commitment, however deeply felt, is no substitute for a consensus arising from collaborative reflection on the practices of a field. Moreover, as the Charleston and Toronto incidents attest, in the absence of any publicly articulated standards, bioethicists have no reason to expect employing institutions to accept an individual's sense of moral propriety as authoritative. If bioethicists are to hold their practices to the same standards of public accountability that they demand of their colleagues in the health care fields—and that these professionals demand of themselves—bioethics organizations need to develop codes of ethics for bioethicists.

CC offered the first code of ethics, if not for bioethicists, at least for the clinical ethics consultation. Unlike the rest of the CC report, however, the code was almost never cited in the literature and had little impact on the field. No bioethics organization moved forward to endorse the code; more surprisingly, the authors of the code never sought any organizational imprimatur, perhaps because a solipsistic conception of the ethics of bioethics seems to permeate the code. CC repeatedly envisions the bioethicist as an isolated solo practitioner whose only guide is personal conviction—left unmentioned is the notion that bioethicists have *professional* as opposed to *personal* obligations. Thus CC notes that individual ethicists may give “advice . . . against an institution's perceived . . . interest” which “may pose potential harms to ethics consultants' *personal* interests” (CC, 5.1.4, emphasis added). It is, moreover, said to be the ethicist's *personal* responsibility not to “shad[e] an opinion to avoid personal risk”

and the individual ethicist's personal responsibility to "either take the risk or withdraw from the case" (CC, 5.1.4). The ethicist is envisioned as a solo practitioner, not as a member of a profession, accountable to others for responsibilities delineated by their role as bioethicists.

It is ironic, but perhaps not surprising, that CC, the first code of ethics for clinical ethicists, portrays reflection on the responsibilities of bioethicists in terms of personal belief rather than professional responsibility. CC reflected the field as it functioned in 1997. At the time, and even today, collaborative reflections on the ethics of bioethical practices were largely absent from the literature. Suppose, for example, that the Toronto bioethicist had turned to the bioethics literature for ethical guidance. A December 3, 2007, *PubMed* search for "hospital, ethics, committees, confidentiality," yielded 70 references; searching for "hospital ethics committee publishing" yielded 13 additional references. Yet although many publications by bioethicists discuss the decisions of hospital ethics committees, none addresses the extent to which decisions of hospital ethics committees are to be considered confidential. By contrast, a December 3, 2007, *PubMed* search of "physicians confidentiality" yielded 2,915 citations on physicians' obligations of confidentiality.

One reason for the disparity is the influence of the solipsistic model: bioethicists still believe that decisions about the propriety of their practices are personal matters; physicians, however, accept that they belong to a profession and have professional responsibilities. Medical societies, in striking contrast to bioethical societies, thus offer detailed statements on physicians' professional responsibilities in specific circumstances. These statements serve as the impetus for most discussions of physicians' obligations of confidentiality in the literature. For example, the first five articles cited in the December 3 search on physicians' responsibility focus on statements by such organizations as the American Academy of Pediatrics Committee on Bioethics (Fallat & Glover, 2007), the American Heart Association and the Emergency Nurses Association (Critchell & Marik, 2007), and the World Health Organization (Ferrario et al., 2007). Presumably, were bioethics societies to issue statements on the ethics of bioethical practices, these statements too would generate a rich literature on the ethics of bioethics.

BIOETHICS, SCANDAL, AND THE NEED FOR A CODE OF ETHICS TO ASSERT PROFESSIONALISM

IN THE OPENING years of the 21st century, bioethicists began to appreciate the need for a code of ethics for reasons that differ from the problems with employing institutions that led to the Charleston

and Toronto incidents. Bioethics was conceived and born in the United States circa 1960–1970,⁴ during a period of political and religious liberalism. The Kennedy-Johnson (and even Nixon) administrations' liberal domestic policies and Vatican Council II (1962–1965) shielded the infant field from conservative political and religious criticism (Baker, 2005b). As the 21st century dawned, Vatican II's influence waned, and conservative Catholics joined with evangelicals and neoconservative politicians to challenge secular bioethics over such issues as the propriety of embryonic stem cell research and the discontinuation of artificial nutrition and hydration—the traditional abortion/euthanasia debates in nontraditional guise.

While these issues played out, commentators from the left and right blended their disparate voices in a chorus of disparaging criticism. The left condemned bioethics as antidemocratic elitism, a secular priesthood who, the right chimed in, abused philosophy to trespass on the traditional social authority of law, medicine, and religion (Shalit, 1997; Siegler, 1999; Smith, 2000). With the election and re-election of the Bush administration (2000–2008), a conservative Catholic-evangelical-neoconservative alliance ascended to power, which the White House used to remove bioethicists and scientists critical of its bioethical policies from government posts.⁵

On another front, critics on the left disparaged bioethics, charging that prestige, power, and money had tempted bioethicists to abandon their watchdog role (Evans, 2001; Stevens, 2000). Public policy and professional journals joined the fray (Elliot, 2001a, 2001b; Sharpe, 2002). To quote the striking prose of one major critic, “If bioethicists have gained any credibility in the public eye, it rests on the perception that they have no financial interest in the objects of their scrutiny.... The problem with ethics consultants is that they look like watchdogs but can be used like show dogs” (Elliot, 2001a). As this critique gained resonance, bioethicists who consulted with biotech and pharmaceutical companies were pilloried in such publications as *US News and World Report* (“And Now Ethics for Sale: Bioethicists and Big Bucks,” Boyce, 2001) and the *New York Times* (“Bioethicists Find Themselves the Ones Being Scrutinized,” Stolberg, 2001).

Yet the bioethicists criticized for consulting with the biotech and pharmaceutical industry thought of themselves as serving the public interest by offering ethical advice to those most in need of it, even as they themselves had to resist pressure to serve as mere show dogs (Perlman, 2005). As in the Charleston and Toronto incidents, everyone felt aggrieved if anyone challenged their personal testimony about the conscientiousness of their conduct. In the absence of any publicly accepted standard of conduct, what defense could anyone offer except to rehearse one's personal belief in one's own integrity?

BIOETHICS ORGANIZATIONS RESPOND

SLOWLY AND UNSTEADILY, bioethics organizations began to respond. In 1998, the bioethicist at the center of the Charleston incident was elected president of ASBH and discussed the incident in her presidential address, "Speaking Truth to Power." In the same year, the CBS responded to the Toronto case by forming an Ad Hoc Working Group on Employment Standards (MacDonald et al., 2000). By 2002, the ASBH had revised its bylaws to permit it to take "positions relat[ing] to academic freedom and professionalism in bioethics." Also in 2002, a joint ASBH and the American Society of Law, Medicine and Ethics (ASLME) task force published voluntary guidelines, *Bioethics Consultation in the Private Sector*, in the *Hastings Center Report* (Brody et al., 2002).

Reformers in both the ASBH and the CBS continued to press for more action. A panel titled "The Public Face of Bioethics: Watchdog or Show Dog"⁶ and a workshop titled "Codes of Ethics"⁷ were featured at the 2002 ASBH national conference. The CBS Working Group on Employment Standards issued a *Draft Model Code of Ethics for Bioethics* that was published on the CBS Web site.⁸ This code asserts a "national standard for ethical conduct in bioethics" because the "social role" that bioethicists play "implies" that they have "fiduciary responsibilities" as "those to whom the public looks for guidance." Despite this language, the *Draft Model Code* retains a lingering solipsism since bioethical obligations are formulated as a personal pledge that, "I will conduct myself in a professional manner" (MacDonald, 2003).⁹ Bioethicists personally commit themselves to eleven obligations: professional integrity, humility, confidentiality, disclosure and recusal, nonauthoritarianism, non-exploitation, professional honor, advancing the field, and integrity in conditions of personal employment and in the employment of others (MacDonald, 2002). Although flawed by lingering solipsism, the draft model Canadian code remains the only code of ethics that enjoys the imprimatur of a bioethics society.

South of the Canadian border, official ASBH action on a code of ethics stalled for 2 years, until Steve Miles, a founding member, resigned publicly. Miles decried the ASBH's "reluctan[ce] or [in]abil[ity] to act on behalf of the threatened academic interests of its members" and its "failure to articulate ... standards of conduct of bioethicists" (Miles, 2004; for response see Board of Directors, 2004). Shortly thereafter, the ASBH formed a Task Force on Ethics Standards and made the ethics of bioethics the subject of a spring conference where attendees discussed a draft code of ethics for bioethicists (Baker, 2005a). The issue gained additional momentum as ASBH president Arthur Derse urged "Ethics Standards for Bioethicists" (Derse, 2005) and as

an ASBH task force endorsed a code of ethics at the ASBH's 2005 annual meeting. At the same meeting, a panel on the ethics of bioethics ended with the organizer, an ageing civil rights protestor, singing "Uncoded," a version of Johnny Cash's tune "I've Been Everywhere,"¹⁰ to chide board members about the ASBH's dilatory attitude toward a code of ethics.

After the meeting, the ASBH board commissioned the Advisory Committee on Ethics Standards (ACES) to survey members about developing an official code of ethics. The ACES committee found that the members supported a code of ethics for bioethicists by a ratio of 3.6 to 1, with 305 of the respondents favoring a code and only 84 opposed (Baker et al., 2006, Table 3.1). Three quarters of the ASBH's members believe that the code should focus broadly on issues relevant to everyone in the field rather than on some narrow area, such as clinical ethics. Members also thought that a code would be most useful to those newly entering the field (Baker et al., 2006, Table 3.3).

Not surprisingly, the issues that the respondents to the ASBH survey thought that a code should address were those that had historically proved vexatious (see parenthetical comments in the following list). About 90% of the respondents believe a code should address:

- ◊ Identifying and disclosing conflicts or interest (scandal headlines),
- ◊ confidentiality and obligations to disclose (Charleston-Toronto issues),
- ◊ reporting serious misconduct (Charleston-Toronto issues),
- ◊ improper pressures by employer/supervisors (Charleston-Toronto issues), and
- ◊ ascribing (co)authorship and crediting contributors to published work.

Seventy percent or more thought that a code ought to address the following two issues:

- ◊ Presenting incomplete characterizations of complex issues in public venues (the Terri Schiavo case) and
- ◊ obligations to report problems to employers, supervisors (Baker et al., 2006, Table 3.4).

Members submitted 88 narratives of incidents raising ethical issues about the practice of bioethics (Baker et al., 2006, Section 5). The wealth of cases makes clear that once bioethicists contemplate the ethics of their practices, a host of issues surface.

CONCLUSION

AS THIS CHAPTER is written, the ASBH Board of Directors is contemplating how best to develop a code of ethics. Code development is a watershed moment in the maturation of a field. The ACES survey found that ASBH members desire a code of ethics to protect their autonomy and integrity and to delineate their values and responsibilities to new entrants. As the Charleston and Toronto incidents established, an effective code must go beyond a statement of principles to provide guidance on the specific issues affecting members and their employing institutions. The challenge is thus to design a transparent, participatory code-development process for a professional society representing a multidisciplinary field that will culminate in a viable code with sufficient specificity to effectively serve the interests of bioethicists, employing institutions, and the public.

NOTES

1. When the Canadian bioethicist Benjamin Freedman proposed a code of ethics for clinical ethicists at a 1986 conference (Freedman, 1989), his suggestion was met with that overly polite condescension that decent people reserve for well-meaning but utterly insane ideas. Everyone changed the subject (Baker, 2007).

2. Some bioethicists are uncomfortable accepting claims of expertise (Parens, 2005; for a response, see Nelson, 2007).

3. Some bioethicists idealize moral solipsism as a virtue (Elliott, 2007).

4. Some scholars date the birth of the bioethics earlier (Jonsen, 1998) or ascribe European origins (Campbell, 2000; Moreno, 2004). I date bioethics from the first appearance of bioethical discourse—including the term *bioethics* itself in 1971—which occurred in American publications during the 1970s. I also distinguish between bioethics and traditional medical ethics. Medical ethics is the self-regulatory ethics of medical professionals, governing their own conduct and their relations with their peers, their profession, their patients, and the public. *Bioethics*, as I use the term, is a multidisciplinary field/discourse addressing ethical issues in the biomedical sciences, as well as in health care, *without privileging* physicians' or scientists' conceptions/discourse.

5. To cite but two examples, in December 2002 the Bush administration removed, Thomas Murray, president and CEO of the Hastings Center, from the Biological Response Modifiers Advisory Committee (Brickley, 2002); in March 2004, it fired scientist Elizabeth Blackburn from the President's Council on Bioethics. Murray and Blackburn were critics of the administration's stem cell policy (Associated Press, 2004; Meslin, 2004—for a defense of the council, see Elliott, 2004; for a general overview, see Mooney, 2005).

6. Panelists: Francois Baylis, Lisa Eckenwiler, and Virginia Ashby Sharp.
7. Organized by Robert Baker with Arthur Derse, Glenn McGee, and Matthew Wynia.
8. The name “Draft Model” was chosen because the double modifier would make “less contentious than a formal code of ethics” (C. MacDonald, personal communication, March 22, 2005).
9. “I thought that it is an important aspect of codes that they are personal. I wanted people to swear to code—also—I didn’t want the code to sound like a list of orders—here is what I expect of myself as a professional in this role” (MacDonald, 2003).
10. Adopted by R. Baker from Geoff Mack’s song “I’ve Been Everywhere.”

Codes are everywhere, man
 Codes are in rulebooks bare, man
 Codes are in the internet air, man
 Everyone’s got their share, man

[List of 38 fields, accountants to zoo keepers, with codes of ethics]

Codes are everywhere, man
 But in bioethics the cupboard’s bare, man
 They are nowhere, man
 They haven’t done their share, man
 For Pete’s sake....
 What a pity
 Cause codes are everywhere, man
 Codes are everywhere

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