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INTRODUCTION

Technological innovations and social developments have led to dramatic changes in the practice of medicine and in the way that scientists conduct medical research. Change has brought beneficial consequences: Americans are healthier and live longer than ever before, and the sick can be helped in ways that were once only imagined. Yet these gains have come at a cost, for many modern medical practices raise troubling ethical questions: Should life be sustained mechanically when the brain's functions have ceased? Should potential parents be permitted to manipulate the genetic characteristics of their embryos? Should society ration medical care to control costs? Should fetal stem cells be experimented upon in an effort to eventually palliate or cure debilitating diseases? As medicine turned to philosophers to help grapple with these types of questions, a new discipline—bioethics—emerged. Bioethicists analyze and assess moral dilemmas raised by medical research and innovative treatments; they also counsel health-care practitioners, patients, and their families.

In this anthology, fifteen philosophers, social scientists, and academic lawyers assess various aspects of this burgeoning field. Some examine the field of bioethics itself, detailing its development and challenging the field's foundational assumptions. Others consider bioethics's role in contemporary society, examining its place in the policy arena as well as how it interacts with other branches of philosophical inquiry. Still other authors focus on specific issues, including: the responsibilities of researchers to subjects in clinical trials; the proper criteria for determining when a living organism has died; the allocation of scarce, life-saving medical resources; and the subsidization of pharmaceutical products for those who may, as a result of their genetic makeup, miss out on some of the benefits modern medicine has brought.

The first two essays in this volume examine important methodological questions in bioethics. Donald C. Ainslie begins his "Bioethics and the Problem of Pluralism" by pointing out a basic tenet of Rawls's political liberalism—namely, that political philosophers cannot approach their field simply by appealing to particular comprehensive moral theories, but must instead recognize the fact that people have basic moral disagreements. This "reasonable pluralism," Ainslie notes, extends to bioethics as well. Surveying several contemporary attempts by bioethicists to deal with pluralism—Tom Beauchamp and James Childress's "principlist" position; Gerald Dworkin's autonomy-based account; and H. Tristram Engelhardt, Jr.'s approach, based on a distinction between "moral friends" and "moral strangers"—Ainslie contends that all three views are problematic. All share the same flaw: each view, in attempting to address pluralism, nev-

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ertheless still grounds bioethical positions on contentious moral views that reasonable people might reject. Ainslie contends that we need to use a different approach, one that uses a “liberal partition” to separate bioethical questions into two categories. In the “bioethics of everyday life,” comprehensive moral doctrines are applied to the issues posed for us by our biological natures. In contrast, in matters of social policy, decisions must take into account that fundamental moral disagreements exist concerning the bioethics of everyday life. As a result, health-care institutions should be structured so that people can live in accord with their own reasonable comprehensive moral doctrines. The two facets of this liberal approach are tightly connected, for policies that promote the ability of individuals to make their own choices depend, for their ultimate success, on individuals making their own choices in principled fashion. In conclusion, Ainslie presents several tensions that arise when the distinction between the bioethics of everyday life and policy-oriented bioethics is not recognized.

Another methodological perspective on bioethics comes from those who argue that a new “pragmatist bioethics” is a necessary next step for the field. John D. Arras examines these theorists’ claims in his contribution to this volume, “Pragmatism in Bioethics: Been There, Done That.” Arras begins by explaining how a pragmatist views the nature of philosophy and the role of the philosopher, and then draws out the implications of this position for bioethics and bioethicists. Pragmatists reject the so-called spectator view of knowledge, according to which knowledge consists of statements that correspond to a separate, external reality. In place of this view, pragmatists argue that knowledge-seekers must be seen as situated in the world that they are studying, and that the knowledge they gain is necessarily colored by their interests, projects, and conceptual schemes. With respect to philosophical questions, this perspective implies that such questions cannot be addressed without thinking about how competing answers would affect human interests. Furthermore, the perspective suggests that philosophy must be informed by work done in other disciplines, particularly the social sciences. Looking at contemporary bioethics, Arras contends that the field clearly reflects both of these general pragmatic insights. Arras then turns to consider how bioethics might draw on a pair of themes from John Dewey’s work on pragmatist methodology—namely, the idea that moral principles are “working hypotheses” and the doctrine of democracy being a way of life. Examining current methodological approaches in bioethics, including recent versions of principlism, Arras concludes that such approaches already incorporate the central lessons that the new pragmatist bioethics wishes to teach. As a result, he doubts whether a refurbished pragmatism can make a distinctive contribution to the methodological ferment present in contemporary bioethics.

The next essay in this volume is a historical account of the study of ethics in medicine. In “The Ordination of Bioethicists as Secular Moral

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Experts," H. Tristram Engelhardt, Jr. argues that bioethics represents a third stage in the development of the philosophy of medicine. In the sixteenth and seventeenth centuries, the philosophy of medicine addressed issues of prescription and classification; in the eighteenth and nineteenth centuries, the field examined how medicine justified its empirical claims. In the 1970s, bioethics emerged as a distinct field within the philosophy of medicine. One consequence was the emergence of secular moral experts whom the public accepted as guides for medical decision-making and health-care policy. In this role, Engelhardt suggests, bioethicists do more than simply analyze issues, assess arguments, or sketch out various philosophical options—they offer normative guidance. Engelhardt attributes bioethicists' ascendance into this role of moral expert to three causes: the deprofessionalization of medicine, the secularization of American society, and a socially perceived need for guidance in questions of medical research and health care. In their new role, bioethicists have become an important political tool: choices in the health-care realm are intensely controversial, and politicians have sought to justify their positions on health-care issues by invoking bioethicists' seemingly authoritative advice. Engelhardt suggests that by being used in this way, bioethicists have become "conceptive ideologists," politically useful tools for those who seek to control important domains of contemporary life.

The next pair of essays in this volume each consider problems with contemporary conceptions of bioethics. In "Information(al) Matters: Bioethics and the Boundaries of the Public and the Private," Lisa S. Parker examines how American bioethics has viewed the public/private distinction. Trying to avoid dogmatism and align itself with the socially powerful medical establishment, bioethics has focused on public-sphere concerns—that is, concerns that arise in the context of professional relationships. Interpersonal, private-sphere questions pertaining to friendships and other relationships of intimacy have been largely neglected. Parker argues that this public-sphere focus has forced bioethics to focus on patients in a general fashion rather than a more nuanced, particularized one, leading the field to develop a view of patients that reflects the values and experiences of middle- and upper-class patients and neglects those of poorer ones. Focusing on public-sphere concerns has also made it difficult for bioethics to address questions in the management of health information (including genetic information), for private-sphere concerns are an important part of informational privacy. Parker contends that bioethics should pay more attention to these interpersonal questions—for example, questions concerning how parents can use genetic information about their future children in making reproductive decisions, as well as questions concerning individuals' duties to disclose information about their genetic makeup to family members. Noting that individuals may appropriately deal with these sorts of questions in different ways, Parker argues that bioethics should not try to find some single "impartial" ap-

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proach to these issues, but should instead encourage the emergence of a patchwork of different ways to respect and protect privacy. By accepting that its own perspective is a partial one, bioethics will lose some of its prescriptive force. However, in sacrificing this authority, bioethics stands to gain as well: the field will acquire new creative power and develop a responsiveness to needs in a broader sphere than it now addresses.

In "Bioethics as Social Philosophy," Kevin Wm. Wildes points out that bioethics is often viewed as simply focusing on moral controversies concerning issues in clinical medicine. Wildes criticizes this view, suggesting that this "controversy of the day" view of bioethics shortchanges the field's role in examining the context in which medical decisions are made. Touching on several of the themes raised in Engelhardt's essay, Wildes examines the rise of bioethics as a field distinct from the philosophy of medicine. He stresses in particular that bioethics's emergence can be partly attributed to advances in medical knowledge and technology, the development of large medical bureaucracies, and the rise of moral pluralism. Given its links to these broad social trends, Wildes maintains, bioethics should be seen not just as a form of practical ethics, but rather as a branch of social philosophy. Wildes builds on this case by discussing the interconnections between the scientific norms of medicine and society's social and moral norms, arguing that medicine is a social construction and that definitions of key medical concepts are socially influenced. After defending this view from criticism, Wildes shows that medicine's nature as a social construction implies that the bioethical study of medicine demands study of society itself—a type of study aided by social philosophy. Wildes concludes his essay by noting that bioethics's grounding in social philosophy is also evident in bioethics's involvement with aspects of public authority. Because bioethics considers questions involving the social allocation of resources, it cannot be divorced from those contemporary questions of ethics and social philosophy that are relevant to debates over distributive justice.

The next two essays each consider epistemological issues. In "Social Moral Epistemology," Allen Buchanan maintains that for applied ethicists—bioethicists included—to provide guidance for right action, they must take into account social moral epistemology, the study of the social practices and institutions that affect the formation, preservation, and transmission of those true beliefs relevant to the functioning of the moral powers, including the moral virtues. In outlining a conception of social moral epistemology, Buchanan notes that applied ethics generally consists of identifying moral principles and developing arguments that support them. Yet in numerous applied-ethics debates, these two tasks have been insufficient to change individuals' behavior. For instance, many physicians still treat their patients in paternalistic fashion, even though philosophers have advanced conclusive arguments against medical paternalism. Understanding this sort of phenomenon requires

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that we examine how socially constructed inequalities perpetuate false beliefs that disable the moral virtues and consequently lead to morally problematic action. Virtue ethicists might stress that their emphasis on moral education accommodates the idea that social institutions and practices affect the moral virtues, but Buchanan argues that virtue ethics does not adequately address social moral epistemology's aims. Virtue ethicists say little about how social institutions and practices affect the moral virtues, Buchanan claims, and they also fail to study how people with a largely successful moral education nevertheless exhibit disabled moral virtues. After suggesting how social moral epistemology is a necessary supplement to applied ethics and virtue ethics, Buchanan goes on to lay out other tasks that social moral epistemology accomplishes: it bolsters arguments favoring liberal political institutions; defends normative ethics's reflective-equilibrium method against important criticisms; and reveals the limitations of metaethical communitarianism, the view that we come to know our moral obligations by locating ourselves within a community's particular traditions.

The reflective-equilibrium method that Buchanan discusses is also examined by Robin Hanson in his essay, "Why Health Is Not Special: Errors in Evolved Bioethics Intuitions." Most fields of applied ethics rely extensively on moral intuitions, using the reflective-equilibrium method to seek the moral position that best reflects both common moral intuitions and the general principles that are supposed to account for them. Hanson argues that intuitions used in considering health-care questions are likely to be error-prone, thus making reflective equilibrium unreliable. Examining various philosophers' accounts of error in moral intuitions, Hanson notes two commonly accepted signs of such error: that an intuition seems excessively contingent in origin, and that an intuition seems to reflect a hidden bias in favor of one's self or a group to which one belongs. Hanson argues that contemporary health-care intuitions exhibit both of these problems. He explains this by examining the roots of these intuitions in evolutionary psychology. Providing health care for others was probably very important to our ancestors as a way of attracting allies and thereby staying alive, and our concern about health care may reflect this ancestral influence. On this account, modern health phenomena are the result of ancient patterns of behavior being reproduced in a vastly different environment. To show that evolutionary psychology accounts for our health-care intuitions, Hanson argues that such a position explains a number of puzzling health-care phenomena. This increase in explanatory power comes at a price, however, for an evolutionary-psychology account of our health-care intuitions suggests that these intuitions are clearly historically contingent and biased in favor of self-preservation. The upshot, Hanson contends, is that we should see our health-care intuitions as being error-prone, and thus that we must, when considering moral questions in health care, rely less on our moral intuitions.

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In “Power, Integrity, and Trust in the Managed Practice of Medicine: Lessons from the History of Medical Ethics,” Laurence B. McCullough maintains that as bioethics has become more interdisciplinary and professionalized, it has become ahistorical, largely ignoring—to the field’s detriment—the work of past medical ethicists. McCullough cites inquiry into the ethics of the managed practice of medicine as an example. Managed practice consists of three important tools: physicians are given economic incentives to use medical resources sparingly, clinical decision-making and behavior are monitored and regulated, and the autonomy of patients is restricted. Implemented in the United States in the 1980s by the Medicare system, these tools have also become the backbone of managed-care organizations in the private sector, and consequently are of fundamental importance to the way medicine is practiced in this country. Yet these three tools faced scrutiny long before the rise of bioethics; criticism of these strategies was an important feature of eighteenth-century British medical ethics. At that time, urban hospitals, known as Infirmaries, used these managed-care tools, and various abuses in this system led to a crisis of intellectual and moral trust, a precursor of recent concerns about managed-care abuses. Three prominent eighteenth-century physician-ethicists—John Gregory, James Gregory, and Thomas Percival—analyzed the crisis of their day, and the result was the development of an ethics to guide the use of power in medicine. Under their direction, medicine was conceptualized as a fiduciary profession in which patients’ interests must be put ahead of the interests of physicians or health-care organizations. McCullough tests the ability of this conception of medicine to address contemporary managed-care issues, arguing that this view brings to prominence central themes of power, integrity, and trust that any adequate account of the ethics of managed care needs. By examining this older view’s implications for modern practice, McCullough shows that bioethics is weakened when its practitioners fail to take seriously the work of their predecessors.

The seven remaining essays in this volume each discuss an applied issue in bioethics. In “The Distribution of Life-Saving Medical Resources: Equality, Life Expectancy, and Choice behind the Veil,” Mark S. Stein argues that choices involving the distribution of scarce life-saving medical resources should be guided by a goal of maximizing life-years. Comparing this allocation policy to others, he points out the strong though uneasy connection of life-year maximization to utilitarian theories of justice. In contrast, other allocation policies—allocating life-saving resources first to the oldest, to the sickest, to those waiting the longest, or to those chosen by the luck of the draw—all emerge from egalitarian theories of justice. Intuitions from various thought experiments underlie Stein’s acceptance of life-year maximization. Life expectancy, he argues, is the only criterion of allocation that, when used alone, does not produce wildly counterintuitive results. Stein also examines a pair of attempts by prom-

inent theorists to use hypothetical-choice approaches to guide the distribution of life-saving medical resources. On these accounts, we ask what we would want done in given situations if there were an equal chance of us being any of the relevant patients seeking treatment. Philosophers Ronald Dworkin and Norman Daniels, both prominent egalitarians, argue in favor of hypothetical-choice approaches. Considering each of their accounts, Stein shows that both allow considerations of relative benefit to play a primary role in the decision-making of hypothetical choosers. The upshot is that both Dworkin and Daniels advocate approaches that are essentially utilitarian, not egalitarian. Stein concludes his essay by examining policies for allocating life-saving organ transplants in the United States, showing that these policies are broadly consistent with his life-expectancy approach and with utilitarianism more generally.

Distributional issues also arise in Arti K. Rai's essay, "Pharmacogenetic Interventions, Orphan Drugs, and Distributive Justice: The Role of Cost-Benefit Analysis." As the amount of genetic information has grown, researchers can better account for why subgroups within a given population with a given disease fail to respond to a medication that works well for a majority of patients. Differences in genetic makeup between the two subgroups cause their members to respond differently to a drug. In certain cases, subgroups that are not helped by current drugs will be too small to provide companies with a market-based incentive to develop a new treatment. Rai considers how government should respond to the problems of these "orphan groups." After discussing how advances in scientific research promise to drastically increase the number of these subgroups, Rai criticizes current law on the ground that it treats all potential "orphan drugs" equally, without regard to criteria that might make certain orphan drugs more worthy of government subsidy. Rai argues that we need to find criteria by which we can decide where to allocate resources dedicated to orphan-drug research. She notes that although moral theory itself does not provide us with definitive criteria, numerous interpretations of distributive justice would recommend using cost-benefit analysis as a tool. After describing the economic structure of drug development and important aspects of medical cost-benefit analysis, Rai shows how such analysis can select some potential orphan drugs as being more cost-beneficial than others, and thus accord them preference when distributional issues are considered. Rai concludes her essay with a discussion of the advantages and disadvantages of a pair of approaches to encouraging orphan-drug development: extending the patent terms for orphan drugs and granting direct subsidies to orphan-drug manufacturers.

The next two essays in this volume each consider issues in the ethics of clinical research trials. In "The Ubiquity and Utility of the Therapeutic Misconception," Rebecca Dresser discusses a widespread and systematic problem in medical research. When offered the choice to enter into a

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research trial, patients generally think that trial participants get the same sort of individualized treatment that one receives in the clinical setting. This “therapeutic misconception” rests on a misunderstanding of the aims of research, Dresser explains. Whereas in clinical care physicians recommend treatments based on what is in the best interests of the patient, research instead aims at generating data in order to assess various treatment options. Toward this end, research studies generally engage in a variety of practices—randomization, blinding, and the use of placebo control groups—that reduce research participants’ ability to get treatment that is individually tailored to their own best interests. Citing numerous empirical studies, Dresser shows that the therapeutic misconception is widespread among patients. Dresser then turns to examine the numerous sources of this phenomenon: the practices of researchers and physicians, government policies concerning research, developments in the private sector, and the portrayals of research by patient advocates and the popular media. Arguing that the therapeutic misconception is inconsistent with acceptance of the principle of respect for persons—a principle requiring that research take place only on individuals who have given informed consent—Dresser notes that current developments in research ethics might well exacerbate the therapeutic misconception. We are faced with a choice: either accept the therapeutic misconception as an inevitable part of the research process, or take corrective action. The latter route may not be easy. Drastic changes may be required to ensure that patients understand the consequences of research participation. However, meekly accepting the therapeutic misconception subordinates the rights of individual patients to the interests of others, an ethically questionable outcome.

The use of randomization in clinical trials is the subject of Robert M. Veatch’s “Indifference of Subjects: An Alternative to Equipoise in Randomized Clinical Trials.” The physician’s duty to do what is best for the patient seems inconsistent with encouraging the patient to participate in a randomized trial, since randomization means that the participant risks receiving treatment that is less than optimal. Traditionally, randomizing trial subjects has been justified by appealing to either individual-clinician equipoise or clinical-community equipoise. Under individual-clinician equipoise, a researcher is ethically justified in encouraging a patient to undergo randomization only if that researcher is ambivalent as to which treatment option is preferable; under clinical-community equipoise, a researcher’s encouragement is acceptable only if the clinical community as a whole has no preference between the treatment options. Veatch notes several problems with both of these approaches: of particular note is his point that a trial subject’s views regarding treatment options may differ from those of his physician or the research community. As a result, Veatch suggests that randomization be seen as ethically acceptable only when individual research subjects are themselves indifferent between treatment options. This view has important implications. First, it supports giving

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patients who are receptive to innovation and risk increased access to experimental treatments. Access is currently denied under policies that only allow people to try these unproven treatments when the clinical community is indifferent about the benefits relative to other options. Second, justifying clinical trials through individual-patient indifference allows researchers to complete trials even if the researchers begin to prefer one particular treatment option. Where clinical-community indifference is the standard for randomization's ethical permissibility, completing a trial becomes immoral once the clinical community believes that one of the trial's treatment options is superior. Using a standard of individual-patient indifference, researchers may continue with trials by using patients who, though informed, may nevertheless remain indifferent between treatment options. A final implication of the individual-indifference standard is that researchers could recruit subjects by offering them incentives that make them indifferent between a study's treatment options. Veatch discusses this possibility, but suggests that such tactics ought not be used.

In "The Biophilosophical Basis of Whole-Brain Death," James L. Bernat argues that an account of "whole-brain death" is the best understanding of death as a biological concept. Bernat contends that much of the disagreement surrounding the criterion of death revolves around disputes over the proper "paradigm of death"—that is, the attributes that one believes "death" must reflect. In Bernat's view, the definition of death must, among other things: be consistent with the term's everyday use as a reference to the end of an organism's life, reflect that death is a biological concept, apply to organisms only, recognize that all organisms must be either alive or dead, and treat death as an irreversible event. Assessing the biophilosophical meaning of "an organism's life," Bernat suggests that a key trait of any living organism is its "critical system," the irreplaceable and indispensable system of controls that permits an organism to maintain itself. The demise of this critical system destroys an organism's ability to function as an integrated whole, and thus represents the organism's death. For higher animal species such as humans, Bernat maintains, the medical criterion representing the demise of an organism's critical system is the permanent cessation of the brain's clinical functions. The upshot of this is that though modern medicine can use technology to preserve the functioning of an individual's organ subsystems, this in itself does not preserve "life": brain function is the key. Locating an organism's critical system in its brain is not the end of the story, however. Questions still remain involving which components of the brain are required for an organism to maintain itself as an integrated whole. Despite these difficult questions, Bernat advocates a whole-brain formulation of the definition of death, which holds that the critical functions of the brain are performed in diverse areas throughout that organ, as opposed to being centered in particular localized regions.

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Contemporary technology allows us to examine an individual's genetic makeup to determine whether one is a disease carrier or is susceptible to a genetic disease. Discussions of genetic screening often refer to the principle of voluntarism, according to which all decisions concerning genetic screening should be made voluntarily by the person to be screened. In "Freedom and Responsibility in Genetic Testing," Baruch A. Brody finds this general principle defective in certain ways. Brody first considers issues of reproductive responsibility. If there exists a genetic disease that causes tremendous suffering to afflicted individuals and a test can be easily administered to identify that disease's carriers, it seems plausible that people have a moral responsibility to undergo that genetic test. This responsibility does not by itself justify compulsory screening. However, Brody argues that various moral considerations that might rule out compulsory screening are ultimately not persuasive grounds of objection. He endorses the administration of certain genetic tests to teenagers as a condition for acquiring a driver's license. Brody next considers access to genetic testing. In some cases, individuals may want to undergo genetic testing for a certain disease, but lack access to the test because physicians do not wish to provide it. Brody notes that analysis of this situation might initially seem unproblematic: physicians have a right to have their choices respected, and thus should not have to test patients. However, physicians often base their refusal to perform certain genetic tests on the claim that these tests are not beneficial to patients. Using a Millian analysis, Brody concludes that the patient may be a better judge of this than the physician. Though Brody does not endorse forcing individual physicians to provide genetic tests, his analysis does suggest that in some cases reluctant physicians should give their patients the tests that they request.

In the final essay, "Genes, Justice, and Obligations to Future People," F. M. Kamm considers a number of ethical issues raised by the idea of altering the genetic makeup of a population. She begins by surveying several positions put forth by Allen Buchanan et al. in their recent work, *From Chance to Choice*, and then turns to an examination of questions raised by these positions. Kamm first examines the so-called Just Creation Question—the question of whether justice requires any particular distribution of beneficial genetic material among people to be created. Fair equality of opportunity, a concept that figures prominently in Rawls's influential account of social justice, might seem to imply that beneficial genetic material should be distributed equally or in maximin fashion. Kamm contests this point. On her view, creators do owe their creations certain important goods, or at least a chance at them. However, once all created individuals have been given an amount of beneficial genetic material sufficient to meet this obligation, inequalities are permissible. In maintaining this position, Kamm considers the discussions of fair equality of opportunity found in *From Chance to Choice* and in Thomas Nagel's writings. Kamm moves on to discuss several other topics in the ethics of

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reproduction, including how, in reproductive contexts, we should understand the duty not to cause harm and the duty to prevent harm; whether it is permissible to treat future persons differently from existing ones; and whether the prevention of future disabled people would have deleterious implications for our attitudes toward disabled people who already exist. Finally, Kamm considers the claim that societal interests and individual interests often coincide; this “Coincidence Thesis” is invoked in *From Chance to Choice* to legitimate the idea that a society could democratically decide to engage in society-wide genetic improvements. Kamm shows that the Coincidence Thesis is problematic. Even if a society only pursued improvements on which there were widespread agreement, conflicts between society and individuals could still arise.

The fifteen essays in this volume question the methodology of bioethics as well as its application to divisive moral and political questions. In doing so, the essays illustrate the impressive breadth of this important new field within contemporary philosophy.

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