

Leon R. Kass

Reflections on Public Bioethics: A View from the Trenches*

ABSTRACT. For many reasons, and more than its predecessors, the President's Council on Bioethics has been the subject of much public attention and heated controversy. But little of that attention and controversy has been informed by knowledge of the Council's mission, its ways of working, and, most importantly, its actual work. This essay describes the Council's mission, discusses its public ways of working, and reviews the five major works produced during the Council's first term. In all its activities, the Council has sought to develop a richer bioethics, one that recognizes and tries to do justice to the deep issues of our humanity raised by the age of biotechnology. Believing that these issues are properly matters to be discussed and governed by the polity as a whole, the Council also has sought to contribute to a genuinely public or political bioethics, beyond the rule of "experts," scientific and bioethical.

In October 2004, I addressed the American Society for Bioethics and Humanities on the work of the President's Council on Bioethics. When I first was invited to speak about my experience with the Council, I was disinclined to do so, preferring instead that the Society engage in a serious examination of one or another of the Council's finished products—more deserving of its attention than my own personal reflections. For I had observed, sadly, that although rumors about the politics of the Council or its relation to presidential politics have received copious public attention, very few people—including some who loudly denounce us and our perceived vices—appear actually to have read carefully what we have written. So the program committee and I made a deal: I first would offer

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some general remarks concerning the Council's work, after which there would be a panel discussion that examined the Council's most ambitious work, *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (PCBE 2003b). This essay represents my half of the bargain, modestly enlarged.

My remarks are divided into three parts: first, a discussion of some special features of public bioethics as our Council has either sought or been compelled to practice it; second, an overview of some highlights of the Council's work to date; and third, some general observations about the task and its challenges. My purposes are also threefold: to set forth how the Council's work has proceeded, especially in relation to surrounding political debates; to provide the first available overview of our substantive work, showing its internal rationale; and to challenge the bioethics community to reflect on the soundness of its intellectual and political assumptions.

THE COUNCIL'S PUBLIC WAYS

Like its predecessor, the National Bioethics Advisory Commission (NBAC), the President's Council on Bioethics is a public body, devoted to public questions, whose activities are fully open to public scrutiny and participation. We, too, were created by Executive Order (Bush 2001a), subject to the rules of the Federal Advisory Committee Act (41 C.F.R. 101.6.10), are required to hold all of our meetings and deliberations in public, and are obliged to solicit views and accept opinions from any and all of our fellow citizens. Like NBAC, we were appointed by and serve at the pleasure of a particular president, charged by him with addressing topics of genuine public import and in service to the public good. Yet some accidents of our origins have made this Council public—indeed, explicitly political—in novel ways.

We were created, after a most vexing electoral process, by a president whose legitimacy was still being denied by many who opposed him and whose pro-life moral views and born-again Christian religious attachments are, let us be frank, strongly held against him in many scientific and intellectual circles. Moreover, our creation was linked to a highly charged single public issue, federal funding of embryonic stem cell research, about which feelings ran and still run enormously high. Indeed, for the first seven months of Mr. Bush's presidency, researchers, biotech entrepreneurs, and patient groups—aided by the President's opponents eager to embarrass him—made the debate about stem cell research a daily front-page story,

where it remained until it properly was displaced by the tragedy of 11 September 2001. (Whether stem cell research *deserves* to be “public bioethics issue number one” is a question we could debate.) The Council and its link to the stem cell question were given enormous visibility when the President heralded the Council’s creation during his televised address on 9 August 2001 (Bush 2001b), announcing his decision on the stem cell research funding question. For all these reasons, the Council came into existence identified as the “stem cell council,” and people on all sides of the embryo research debate seem to care more about the Council’s views on this subject than about anything else. Not by our choice—and certainly not by mine—the Council was born smack in the middle of “embryoville,” and it never has been able to leave this highly political field.

Congress was responsible for a second major step toward politicizing public bioethics—I mean this literally, in a neutral, descriptive sense. Shortly before the Council was formed, throughout the spring and summer of 2001, Congress was debating anti-cloning legislation. For the first time since it had passed laws banning the buying and selling of organs for transplantation, Congress was considering criminalizing certain biotechnical practices, in this case, precisely identified activities of human cloned embryo research and clonal reproduction. In July 2001, the House of Representatives had passed by a wide margin the Weldon-Stupak bill banning all human cloning, whether for research or baby making (The Human Cloning Prohibition Act of 2001 [HR 2505]), and similar legislation was under review in the Senate. Perhaps for the first time ever in Congress, a moral argument was prevailing against scientific innovation in order to stop an ethically controversial practice, overcoming, at least for the time being, passionate claims that cloning research would lead to cures for millions. When the President later asked the Council to weigh in on the cloning question, we found ourselves in the midst of an ongoing political debate about the morality of innovation. We were not merely advising on possible future directions or recommending administrative guidelines to the NIH for an already acceptable practice; we were discussing legislation that would put transgressing scientists in jail. We would take this political burden very seriously: it meant, among other things, the need to speak both carefully and fairly, yet in terms that the general public would understand—not in abstract academic jargons or the “bureau-speak” of governmental regulatory bodies.

But when the Council was officially created in November 2001, its designated charge was enormously broad, both in scope and in spirit, not

narrowly political or policy-driven. Indeed, the duty to monitor stem cell research is not mentioned explicitly in the executive order establishing the Council (Bush 2001a). Unlike NBAC, whose charter tied it “as its first priority” to specific issues of human subjects research (OSTP 1996), the executive order that created our Council lists our functions in staggering terms:

The Council shall advise the President on bioethical issues that may emerge as a consequence of advances in biomedical science and technology. In connection with its advisory role, the mission of the Council includes the following functions: (1) to undertake fundamental inquiry into the human and moral significance of developments in biomedical and behavioral science and technology; (2) to explore specific ethical and policy questions related to these developments; (3) to provide a forum for a national discussion of bioethical issues; (4) to facilitate a greater understanding of bioethical issues; and (5) to explore possibilities for useful international collaboration on bioethical issues.

Our first listed function is deeply philosophical, anthropological, and cultural, and it gives this Council a novel orientation: we are charged first not to judge whether deed “x” or “y” is moral or immoral, or whether technology “p” or “q” should be funded or banned. We are summoned to search into deep human matters in order to articulate fully just what is humanly at stake at the intersection of biology and biography, where life lived experientially encounters the results of life studied scientifically. This means, for example, enquiring not only about whether the cloning technique is safe, but about what it would mean for inter-generational relations should children arise not from the coupling of two, but from the replication of one, or for the character of society should procreation be turned evermore in the direction of manufacture. This means asking not only about genetic privacy or genetic discrimination, but also about what it means to acquire godlike powers of deciding which genetic defects disqualify one for birth or to view human identity increasingly through the lens of inborn genetic dispositions. This means asking not only about issues of health or unfairness when athletes take steroids or students take stimulants, but also about whether and how these and other enhancement technologies might distort the character of human activity or change the ways in which we live together.

In brief, our first charge is a mandate to raise questions not only about the best means to certain agreed-upon ends, but also about the worthiness of the ends themselves, a mandate to be clear about all of the human

goods at stake that we seek to promote or defend. It is a call to restore to public bioethics the concerns that gave rise to the field in the late 1960s and early 1970s: Where is biotechnology taking us? What does this mean for our humanity? What kind of people do we wish to be, and what sort of a society do we wish to become? We are charged once again to thicken and enrich public bioethics discourse, away from the more limited, explicitly practical approaches adopted by the collaboration of scientists/physicians and professional bioethicists through the work of previous national commissions and regulatory bodies.¹

To be sure, we also are charged with exploring specific ethical and policy questions: our task is not merely philosophical, but also practical and political. Our task comprises not only analyzing and offering advice on the specific ethical and policy issues, but also providing a forum for national discussion and deliberation of these issues. Finally, we are given a clear educational function: given the immense complexity and difficulty of the bioethical issues before us, we have a duty to promote a greater understanding of these issues for a wider national public. We are to probe philosophically, advise politically, and teach publicly—each a very tall order, together, perhaps impossible.

In subject matter, our scope is as broad as our functions are wide. We are free to “study ethical issues connected with specific technological activities, such as embryo and stem cell research, assisted reproduction, cloning, uses of knowledge and techniques derived from human genetics or the neurosciences, and end-of-life issues” (Bush 2001a). But we are free also to “study broader ethical and social issues not tied to a specific technology, such as questions regarding the protection of human subjects in research, the appropriate uses of biomedical technologies, the moral implications of biomedical technologies, and the consequences of limiting scientific research.” Save where we receive specific requests from the President, the Council is free to set its own agenda and priorities, based on criteria of perceived gravity and urgency. And that is exactly what we have done, without any interference. The Council’s work has been entirely free from any political manipulation or meddling by the White House. Indeed, the White House, although kept abreast of the subjects we are pursuing, sees the Council’s work for the first time only the day before it is made public, with copies of reports delivered as a courtesy to the President on the afternoon before they are released.

The Council’s scope is broad, so its manner of enquiry is searching and open. The Council is, by design, in every respect a diverse and heteroge-

neous group. By training we are scientists and physicians, lawyers and social scientists, humanists and theologians; by political leaning we are liberals and conservatives, Republicans, Democrats, and independents; and by religion we are Protestants, Catholics, Jews, and perhaps some who are none of the above. Although we are a Council *on* Bioethics, we are not a council *of* bioethicists, although four of the original 18 members are fellows of the Hastings Center.² We are called to the work of public bioethics not as “experts” practicing a particular academic discipline, but simply as thoughtful, wisdom-and-prudence-seeking human beings who recognize the supreme importance of the issues arising at the many junctions between biology, biotechnology, and life as humanly lived, and who accept the obligation to try to improve public governance in these matters. A bunch of smart, diverse, morally serious, and practically engaged people were turned loose on bioethical questions, precisely because the questions are at once deeply human and deeply public.

Speaking of our diversity, I hasten to add that there were no political or ideological litmus tests for appointment to the Council, not the first time around, and not at the start of our second term. Of the original 18 members, probably seven or eight did not vote for President Bush, and no one asked. Nor was there ever any litmus test on the embryo questions. It is time to put to rest the libel that the Council is a hyper-politicized group of right-wing fundamentalists, seeking to impose pro-life views on the nation or willing to ignore scientific facts in the name of religious ideology. These charges were made about us even before our first meeting—writing on the day we first met, a *Washington Post* reporter (Weiss 2002) compared us to the Taliban—and, sadly, they continue, despite copious evidence, via our transcripts and published reports, to the contrary.

The proof of Council heterogeneity probably comes as cold comfort for any scientist whose only issue is stem cell research and whose only bioethical cause is overturning the Dickey amendment (P.L. 104–99 (1996)),³ which prohibits federal funds from being used to support any research in which human embryos are harmed or destroyed, and the Bush stem cell research funding policy, or, conversely, for any right-to-lifer for whom stem cell research is also the only important issue, but who demands the opposite result. Against such critics, left and right, I must insist that it is misguided to make embryo research the litmus test for intellectual probity and intellectual seriousness in bioethics. Yet for those who like such litmus tests, here is a fact worth remembering: this council is the most intellectually diverse national bioethics commission in recent history when it comes

to embryo research—and, I would submit, when it comes to most other things. We have members who believe that embryos are inviolable human persons and members who believe that embryos are simply clumps of cells, and lots of us who believe something in-between. We have members who believe that embryonic stem cell research is unduly hampered by the Bush funding policy and members who believe that embryo research should be banned entirely. Like the rest of the country, the President’s Council on Bioethics is divided on the ethics of embryo research. The same could not be said of the National Bioethics Advisory Council that served under President Clinton, a serious body that did some very valuable work, but a body without a single vote against embryo research—and no bioethicists, I believe, petitioned to complain.

All that said, I think stem cell, or other, litmus tests do public bioethics little good and great harm. The embryo research question is, to be sure, important, and it has emerged as the predominant public bioethics issue of the current moment. But it is wrong to presume that people who hold similar positions on the ethics of embryonic stem cell research are intellectual clones, just as it is wrong to presume that people who disagree on the embryo question do not share many other intuitions about the meaning of biomedical progress. (This is, as I discuss below, one of the Council’s greatest practical achievements: a series of consensus recommendations on the regulation of reproductive biotechnology, by a group of people with radically different positions on embryo research.) To see all of bioethics through embryonic eyes is to miss much that matters, and to distort much of great importance.

Because we deliberately were constituted to embrace differences of views and to deal with fundamental issues, and because reasonable and morally serious people often disagree about fundamental issues, it is fortunate that we were liberated from an overriding concern to reach artificial consensus that would have papered over these differences—another crucial difference between our Council and its predecessors. For there are only two ways to get consensus in such a public body: either stack the council, losing all credibility, or seek agreement on the lowest common denominator issues—e.g., human cloning is “at this time” unsafe—leaving all the big questions for some other body. In pursuit of our goal of comprehensive and deep understanding, as our Executive Order indicates, “the Council shall be guided by the need to articulate fully the complex and often competing moral positions on any given issue . . . [and] may therefore choose to proceed by offering a variety of views on a particular issue, rather than attempt

to reach a single consensus position” (Bush 2001a). And that is exactly what we have done. All serious relevant opinions, carefully considered, have been welcome. We also have sought out viewpoints not represented on the Council through reading and invited testimony and through public comment, oral and written. Moreover, each Council member knows he or she has the right to say whatever he or she wishes and to dissent explicitly in whole or in part from any part of any report—a right that all of us have chosen to exercise in print.

Let me try to draw together some threads regarding the Council’s way of working. (1) We aspire to a richer bioethics, debating ends as well as means, and self-consciously committed to articulating the full range of human goods that we are eager to promote and defend. (2) We aspire to address the President and the polity on clearly political issues—issues important to the polity as a whole—and not merely administrative or regulatory ones, and we aspire to do so in the ordinary terms of public discourse. (3) We aspire to a full and comprehensive airing of the issues, making the best case we can both for and against any proposed line of thought or action. (4) This means, in sum, that we are in microcosm, and in the best sense of the term, a *political* body (albeit one without political power): there will be deep disagreements about crucial issues; partisans on all sides will dislike some or all of what we have to say; and our ability to affect special policy may be limited, especially as we deal with intractable, hotly divisive public issues, such as embryo research. We can, however, try to model reasoned and respectful discourse, to increase public understanding of the issues, and to improve the way in which we as a nation deliberate about these matters.

THE COUNCIL’S WORK

In its first two-year term, which concluded in January 2004, the Council (crazily!) undertook five different projects, and by the beginning of April 2004, it had published sizeable volumes on all five. From a greater distance, it might be possible to try to assess the quality of the Council’s work and, more importantly, its possible impact—whether on the degree of public understanding, the shape of the national debate, the character of ethical reflection, or on specific legislative or policy initiatives. It is too early for such an assessment, and I, in any case, am still too close to the daily business of the Council’s work to have either the leisure or the necessary detachment. I content myself here with summarizing what we have done in a way that tries to reveal its internal logic and rationale and, where ap-

appropriate, offer a few evaluative comments of my own. Although the true merit and importance of the Council's work is for others to judge, I will say that I am very proud of what the Council has produced—of its breadth, its depth, its moral seriousness, its accuracy in presenting scientific data, its fairness in presenting moral argument, and its overall judiciousness. Regardless of whether the answers we suggest are right, we surely have been struggling with important questions.

The five published works of the Council—produced within 26 months—are diverse in their subjects, their specific goals, and their forms; yet in complementary ways they all try to embody our search for a richer bioethics. *Human Cloning and Human Dignity: An Ethical Inquiry* (PCBE 2002) addresses the very limited, but timely, topic of human cloning—what to think and what to do about it—and offers specific legislative recommendations. (Although we took testimony from others, the analysis and proposals are entirely our own work.) *Monitoring Stem Cell Research* (PCBE 2004a) responds to the President's request for an update on developments concerning human stem cell research, both in basic and clinical research and in the ethical and policy debates, as these had emerged under the current federal policy. (In preparing the report, we analyzed and commissioned reviews of the work of others, but we offer no arguments of our own and no recommendations.) *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (PCBE 2003b), a purely educational work with no policy recommendations, surveys the growing powers that biotechnologies are providing to serve nonmedical ends—such as the strong human desires for “better children,” “superior performance,” “ageless bodies,” and “happy souls”—seeking to raise public awareness of the challenges that such pursuits might pose to the meaning of our humanity. *Being Human: Readings from the President's Council on Bioethics* (PCBE 2003a) offers a rich anthology of readings that can help one better appreciate and promote those aspects of our humanity that are especially implicated by the coming age of biotechnology—readings that serve as resources for thinking about, for example, the very questions raised in *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (2003b) and the other Council reports.⁴ Finally, *Reproduction and Responsibility: The Regulation of New Biotechnologies* (PCBE 2004b) tries to address the large social and political question of how to monitor, oversee, and regulate the development and uses of new biotechnologies, so as to reap their benefits while avoiding their harms, how to exercise control over where biotechnology may be taking us in order to both serve and preserve our humanity. (Although it is but a

preliminary and mainly diagnostic document, assessing current regulatory practices en route to further exploration, the report also offers unanimous interim recommendations, calling for increased data gathering, improved professional self-regulation, and modest legislative moratoria.)

In brief, the Council has analyzed and spoken to a current legislative debate, monitored a complex area of research and vexing policy arguments, organized in a humanistic way a big picture of “enhancement” uses of biotechnology, provided materials for deeper public understanding of basic questions, and begun the search for a way to govern the burgeoning powers of biotechnology. What follows are a few specific comments on each project, trying to hit some of the high points.

Human Cloning and Human Dignity: An Ethical Inquiry

Although our cloning report (PCBE 2002) was prepared in a climate of intense lobbying and legislative maneuvering, we chose to take the high road, exploring thoroughly all aspects of the topic—anthropological, scientific, ethical, and political. The media was, of course, interested only in the Council’s divided legislative recommendations—and more in the fact that they are divided than in their substance—but the report, by design, is intended to model our thoroughgoing approach, addressing issues of larger humanistic significance, yet also attempting prudent assessment of various courses of possible public action. Several features of this report deserve special attention.

First, we begin not with the techniques of cloning, but with the larger human contexts in which controversies over this innovation must be considered: the character of human procreation, the moral meaning of healing and the value of biomedical research, the tacit ethical contract between scientists and society, and the worth of human life in all its various stages.

Second, in perhaps the most cogent chapter of the report, “On Terminology,” the Council clarifies the terminology that confounds public discussion, beginning with “human cloning” itself, which—regardless of the purpose for which cloning is undertaken—we believe names the act that produces the genetic “replica,” the creation of an embryonic clone. By using accurately descriptive terms, “cloning-to-produce-children” and “cloning-for-biomedical-research,” we could debate the moral arguments without Orwellian or euphemistic distortion. Whether one favors or opposes cloning-to-produce-children, or cloning-for-biomedical-research, everyone must acknowledge that both uses of cloning begin with the same

act: the production of cloned human embryos. On this point, all members of this divided Council agreed.

Third, the Council, in unanimously opposing cloning-to-produce-children, argues not only that the practice is demonstrably unsafe, but that it never could be attempted safely. Moreover, most council members opposed this practice for more than reasons of safety; we were concerned that it could, in various ways, imperil the freedom or dignity of the cloned child, the cloning parents, and the entire society. By enabling parents for the first time to predetermine the entire genetic makeup of their children, it would move procreation toward a form of manufacture. It would confound family relations and personal identity. And it might open the door to a new eugenics.

Fourth, regarding cloning-for-biomedical-research, the Council, like the nation, was divided. On the one hand, this research offers the prospect—although speculative—of gaining valuable knowledge and treatments for many diseases. On the other, it requires the deliberate creation, exploitation, and destruction of nascent human life, it probably makes cloning to produce children more likely, and it risks coarsening our moral sensibilities. Although individual Council members weighed these concerns differently, quite remarkably we all agreed that each side in this debate is defending something *vital to us all*: the goodness of knowledge and healing and the goodness of human life at all its stages. In this spirit of shared moral seriousness, we adopted a novel form to present our views on this subject: the entire Council authored a chapter in which the moral case for and the moral case against cloning for biomedical research are given full-throated defenses and an effort was made by all of us to make both cases as strong as possible. Individually, we favored different stances, but collectively we owned the full debate as worthy of everyone's attention.

Finally, we offered two alternative policy recommendations, both distinct from the most prominent legislative proposals in Congress. Both recommendations call for a permanent ban on cloning-to-produce-children. Regarding cloning-for-biomedical-research, a minority of the Council recommended that such potentially valuable research proceed, but *only if and when significant and enforceable regulations are in place*, including federal licensing, effective oversight procedures, and strict limits on how long cloned embryos may be allowed to develop. A majority of the Council, myself included, recommended that no human cloning of any kind be permitted at this time, proposing a four-year federal moratorium on all human cloning, including cloning-for-biomedical-research. With

both parties to the congressional debate wedded to their separate positions, and at that time each still confident of eventual victory, neither recommendation of the Council picked up any support. The Council has, however, not wavered in its views on this subject.

Monitoring Stem Cell Research

Despite the fact that stem cell research was seen by nearly everyone to be our major business, this report has received very little notice or comment. Because the field and the current policy are so young, the *Monitoring Stem Cell Research* report (PCBE 2004a) could be no more than an update. It summarizes some of the more interesting and significant developments between August 2001 and July 2003, both in the basic science and medical applications of stem cell research, and in the related ethical, legal, and policy discussions. Containing no guidelines or recommendations for public policy, it sought rather to shed light on where we are now in these early days—ethically, legally, scientifically, and medically—in order that the President, the Congress, and the nation may be better informed as we continue to consider where we should go in the future. The report sought not to settle the public debate, but to improve it, for public discussion of stem cell research in the past three years has suffered often from great confusion, with all sides, frankly, willing to distort the truth for political advantage.

The report has four basic goals: to explain and clarify the existing federal policy regarding taxpayer funding of stem cell research and to review its implementation; to provide a coherent overview of the public debates surrounding stem cell research; to provide an update on scientific developments in all areas of human stem cell science since President's Bush's funding policy went into effect; and finally—an overarching goal—to convey the moral and social importance of the issue at hand and to demonstrate how people of different backgrounds, ethical beliefs, and policy preferences can reason together about it in a constructive and publicly responsible way.

A major contribution of the report is its clear explanation of the present federal funding policy: its character, its rationale, and its implementation. If one wants to quarrel with the policy, one should know what it is and on what grounds it rests. The policy—not, as some falsely claim, a ban, but, for the first time, limited public funding for embryonic stem cell research—is founded on (1) a desire to promote important biomedical research (2) without using taxpayer funds to endorse, support, or create incentives

for the future destruction of human embryos and (3) without violating the boundaries set by existing federal legislation. The report describes this aim in the context of the history of federal funding of embryo-related research, including the critical Dickey Amendment, which, as noted earlier, prohibits federal funds from being used to support any research in which human embryos are harmed or destroyed. The report also articulates the legal, ethical, and prudential foundations of the current policy, noting in its discussion of the meaning of governmental support that a federal funding decision is always ethical, as well as economic, in character, pronouncing official national blessings upon the activity being funded.

We lay out the basic facts regarding the implementation of the administration's funding policy, explaining how NIH has put the policy into action and clarifying where things stand in terms of available funding and available cell lines. We clear up the confusion between *eligible* stem cell lines—those derived before 9 August 2001—and *available* lines—ones that have been characterized to the point that, with suitable material transfer agreements, they are ready for use by researchers. There are indeed 78 eligible lines, with 23 lines now available, up from one in Fall 2002 and 12 in Fall 2003. With the aid of FDA testimony, we also discuss and give reassurance against the complaint that the eligible lines are useless for clinical work because they have been grown with the aid of mouse feeder cells—a charge that now gets ratcheted up as “contamination by mouse cells.”

The longest chapter of the report provides an overview of the ethical and policy debates, describing and organizing all the major strands of the public debate and presenting them so that people may easily see the issues, the arguments, and the opinions on all sides that merit everyone's serious consideration. We took pains to organize the discussion in relation to the current policy and its moral and prudential underpinnings so that the reader may see the way in which the ethical debate can have practical traction regarding policy. Subtopics include challenges to the moral aims of the current policy, challenges to some of the policy's internal features, efforts to try to cut the Gordian knot that is the moral standing of human embryos, and other social and public issues less frequently discussed but perhaps no less important. The Council concluded that, at least for now, neither side to the debate seems close to persuading the other of the truth it thinks it sees, but the rich and growing ethical debates do suggest the possibility of progress toward greater understanding of the issues, and toward more informed public decision making, as all parties to the delib-

eration appreciate better just what is at stake, not only for them or their opponents, but indeed for all of us.

Finally, the report provides both an explanation of what the science of stem cells involves, and an update on recent developments in the current state of human stem cell research, understanding, of course, that the field is always changing. The report contains seven commissioned review articles written by leading scientists covering the published literature on embryonic stem cells, embryonic germ cells, adult stem cells, multipotent adult progenitor cells, mesenchymal stem cells, stem cells from cloned embryos, and the problem of immunological rejection. These papers appear unedited and in their entirety. In addition, there is a staff-written chapter to enable readers, especially those who are not scientists, to appreciate the reasons for the excitement over stem cell research, the complexities of working with stem cells, some early intriguing research and therapeutic findings, and the difficult road that must yet be traveled before society can reap therapeutic and other benefits from this potentially highly fertile field of research. The report is, all in all, a sober update, reporting on the promise without the hype, and enabling people to think more clearly about how well the current policy is working. Yet in the electoral year of 2004, our report had no effect in preventing the demagoguery that was everywhere loose on the subject.

Beyond Therapy: Biotechnology and the Pursuit of Happiness

Our third report, *Beyond Therapy* (PCBE 2003b), explores the significance of present and projected uses of biotechnology to serve human goals beyond healing disease and relieving suffering and to satisfy widespread human desires. This report differs from anything that previous bioethics councils have done, and it is perhaps more than our other work a reflection of our interest in a “thicker” and “richer” bioethics. For in it we are not so much concerned with the familiar and important issues of safety, or equitable access, or privacy and discrimination, or the need for informed consent in acquiring and using biomedical knowledge and technique—the staples of much bioethical assessment. Rather, we are emphasizing questions about what should be done with the new abilities to alter human genes, bodies, and minds—assuming the techniques to be safe, freely chosen, and equitably available: what goals should they serve? How might they alter our lives and those of future generations, both as individuals and as a society? These new “beyond therapy” possibilities will force us to face tough questions about the wisdom of our ends, as

well as about the benefits and harms of pursuing even our worthiest ends by these new biotechnological means.

When new technologies are employed in conventional medicine, the answers about ends are quite clear. We want to heal the sick. We want to relieve the suffering. And our new abilities might let us do so more effectively. But when the same technologies enable us to reach beyond the traditional goals of medicine to alter our bodies and minds for ends other than restoring health, we are in uncharted waters. We must consider seriously what those ends should be and what price we might be forced to pay for pursuing them biotechnologically.

Instead of structuring its discussion around the technologies themselves, the Council decided to organize its reflections in this area around the desires and the goals that either drive human interests in these techniques or will enlist the available powers they make possible: desires for longer life, stronger bodies, sharper minds, better performance, happier souls, better children. Such an approach enables one to consider how these new powers fit with previous and present human pursuits and aspirations that are not necessarily mediated by technology (or biotechnology). It also makes clear that the most fundamental issues here are questions of human character, desire, and aspiration—and their malleability—rather than questions of new techniques and the powers they provide.

Beyond Therapy is in six parts. After an introduction that lays out the reasons for the study, there are four central chapters: “Better Children,” “Superior Performance,” “Ageless Bodies,” and “Happy Souls.” In each, we explore the meaning of the goal, evaluate the possible new means for achieving that goal, and, most important, examine critically some plausible ethical and social implications of possible success. The sixth and final chapter offers general reflections that try to put things together.

In the second chapter, under the heading of “Better Children,” we take up new technologies that might enable us to improve our children’s native capacities through genetic knowledge and their behavior or performance through pharmacological intervention. Should preimplantation genetic diagnosis (PGD) be used only to prevent disease or also to try to generate better children, by selecting for genes that might be related to some desired trait or aptitude? Should we choose for sex, which in technical terms is already relatively easy to do? Or, turning now to behavior, should we use stimulants, effective in treatment of attention deficit disorders, to improve concentration or to control behavior in children who do *not* meet the diagnostic criteria for attention deficit (or any other) disorder? Should

they be used to aid test takers or to improve mental stamina? And what would it mean if they became widely used for such purposes?

Attention to such issues leads to deeper questions about the meaning and limits of parental control, the character and growth of children, risks of social control and conformity, the medicalizing of moral education, and, finally, the meaning and goodness of “being a child.”

The third chapter asks what it means to seek superior performance using technologies of genetic or pharmaceutical enhancement, for example, injecting genes into muscles to improve dramatically their strength and endurance. The discussion focuses on enhanced athletic performance, both because it clearly highlights the crucial issues and because it permits easy examination of the differences between more traditional methods of enhancing performance and the newly arriving biotechnical ones. Central to the analysis are questions about the *excellence* and the *humanity* of excellent human activity. The Council also considers how new approaches to superior performance might affect the way people act in the world, conceive of their own bodies, regard their identities, and value their own activity.

The fourth chapter addresses technologies that aim to satisfy the desires for ageless or ever youthful bodies. It surveys the latest advances in aging research, including some astounding extensions of life in worms, flies, mice, rats, and other laboratory animals, and explores the potential implications of such research for extending human longevity and increasing the maximum life span. The Council considers techniques both modest and bold, from near-at-hand interventions to increase the vigor of muscles or the function of memory to more futuristic efforts to retard the general processes of biological senescence. The central question is this: Should we seek to retard aging only to diminish the physical and mental infirmities of old age or also to engineer larger increases in the maximum human life span? We recognize the obvious and powerful appeal of such innovations, but raise questions about how the human experience might be different in a world of super-longevity and how longer life might affect individual outlooks, engagements, and motivations, as well as the dynamic character of society, relations between the old and the young, and prospects for society’s invigorating renewal.

The fifth chapter looks at the powerful desire for happy or contented or satisfied souls, pursued using drugs that directly alter memory and mood, among other things. Should these technologies be used only to prevent or treat mental illness or also to blunt painful memories of shameful behavior,

transform a melancholic temperament, or ease the sorrows of mourning and diminish the anguish and stresses of everyday life?

Central to the analysis are questions about the connection between experienced mood or self-esteem and the deeds or experiences that ordinarily are their foundation, as well as the connections between truthful remembering and personal identity. We also ponder what the availability of chemicals to correct our discontents will do to the nature of human aspiration or the character of our society more generally.

The final chapter argues that all of these efforts “beyond therapy” are in fact part of one big picture: the pursuit of happiness and perfection in the age of biotechnology. This new prospect requires us to think beyond issues of safety, fairness and equality, freedom and autonomy, and to consider issues of hubris and humility, identity and individuality, the dignity of human activity, and the difference between partial ends and full flourishing. It also forces us to look at social issues: the manufacture of new desires by commercial interests, the interpretation of much of life through the medical model, and the unprecedented challenge to the American ideals of liberty and equality. How shall we live in years to come empowered by biotechnology? What kinds of human beings and what sort of society are we likely to create and at what gains and costs to our humanity?

Our ability to deal well with these prospects will be helped greatly if we begin now to think through their human and ethical significance. We do not pretend to see the future, and Council members, not surprisingly, sometimes differ on questions of scientific likelihood or ethical emphasis. But we all agree that we have identified the crucial questions, and we insist that the need to address them is not simply futuristic. Current trends make it perfectly clear that the push beyond therapy is already upon us, and we would do well now to give this subject serious thought.

*Being Human: Readings from the President’s Council on Bioethics*⁵

The Council has noted often, and already had done so when we first convened in January 2002, that many of the deepest human implications of the coming age of biotechnology are not now receiving adequate attention. Perhaps it is because the field is so busy attending to the novel bioethical problems that emerge almost daily. Perhaps it is because attention to devising guidelines and regulations leaves little time to reflect on the full range of human goods that we should be trying to promote or protect. But it may also be that the concerns and concepts most prominent in academic and public bioethics—concepts derived largely from medical

ethics and the ethics of human subjects research, rather than, say, from the philosophy of technology or philosophical anthropology—do not by themselves, for all their strengths, get to the deepest reaches of our subject. We are quick to notice dangers to life, threats to freedom and autonomy, and risks of discrimination or exploitation. But we are slow to think about the need to uphold human dignity and the many ways of doing and feeling and being in the world that make human life rich, deep, and fulfilling. Indeed, it sometimes seems as if our views on the meaning of our humanity have been so transformed by the technological approach to human life that we may be in danger of forgetting what we have to lose, humanly speaking.

To enlarge our vision and deepen our understanding, we need to focus not only on the astonishing new technologies, but also on those—in truth, equally astonishing—aspects of “being human” on which the technologies impinge and which they may serve or threaten. Bioethical dilemmas are not technological but human dilemmas—individual, familial, social, political, and spiritual—confronted by human beings living in various stages of the human lifespan, embedded in networks of meaning and relation, and informed by varying opinions and beliefs about better and worse, right and wrong, and how we are to live. Both in practice and in our self-understanding, bioethical issues generally touch matters close to the core of our humanity: birth and death, body and mind, sickness and health, sex and procreation, love and family, identity and individuality, freedom and dignity, aspiration and contentment, the purposes of knowledge, the aims of technology, the meaning of suffering, the quest for meaning. A richer bioethics would attend to these matters directly and keep them central to all bioethical enquiry and judgment. A richer bioethics would feature careful and wisdom-seeking reflection regarding the full range of human goods at stake in bioethical dilemmas.

Since the beginnings of human self-consciousness, birth and death, freedom and dignity, the meaning of suffering, and all the other marks of a genuinely human experience have been the subjects of humanistic reflection and writing, capturing the attentions of great thinkers and writers. Works of history, philosophy, poetry, imaginative literature, and religious meditation have pondered and commented upon—and continue to ponder and comment upon—these matters. In the Council’s own discussions and reports, we have, on several occasions, looked to these works for their insights and instruction. (Roughly a dozen of the works included in this volume explicitly have entered the conversations at our meetings or the

pages of our writings.) And each of us individually, explicitly or tacitly, relies on what we have learned throughout our lives from texts such as these, as we grapple with the difficult bioethical issues before us. Recognizing the value of such readings, we have featured many selections in our “Bookshelf” link, a substation on the Council’s website (*www.bioethics.gov*). In keeping with our charge “to facilitate a greater understanding of bioethical issues,” we have collected and organized these resources in an anthology of 95 readings, published in the hope that others may discover for themselves the help that is available from wise, sensitive, and thoughtful authors, many of whom come from other times and places. As we strive to *stay* human in the age of biotechnology, in ever-better and fuller ways, we must take whatever help we can get in deepening our appreciation of “*being human*.”

The readings are not presented as authoritative or as authorities. They differ too much among themselves to constitute any single coherent teaching. Rather, we offer them in a wisdom-seeking—rather than wisdom-delivering—spirit, as writings that make us think, that challenge our unexamined opinions, expand our sympathies, elevate our gaze, and illuminate important aspects of our lives that we have insufficiently understood or appreciated.

The book is organized into 10 chapters, in three sections. The first section, “Natural Imperfection and Human Longing,” introduces a central human question that lurks beneath the surface of many bioethical issues: Which is the proper human attitude or disposition in the world: molding or beholding? When and to what extent should we strive to change and alter nature and especially our own given nature, in an effort to improve or save it? When and to what extent should we strive to accept and appreciate nature and our own given nature in an effort to know or savor it? This section, comprising three chapters—“The Search for Perfection”; “Scientific Aspirations”; and “To Heal Sometimes, To Comfort Always”—also introduces the means we have for acting upon these dueling impulses and longings: biomedical science and the art of medicine, both major players in the dramas of bioethics today.

The second section, “The Human Being and the Life Cycle,” moves from aspirations of and for human beings to questions about human nature itself: What *is* a human being? And what sort of a life have we human beings been given to live? The four chapters comprising this section—“Are We Our Bodies?”; “Many Stages, One Life”; “Among the Generations”; and “Why Not Immortality?”—treat several aspects of

these anthropological questions, many of them sorely neglected in much current bioethical discourse, whose emphasis on personhood, autonomy, and consciousness is overly focused on matters mental. This section of *Being Human* considers the meaning for our identity of our embodiment; the tension between change and stability as we progress through the life cycle; the place of begetting and belonging in human flourishing, as we live with ancestors and descendants; and the meaning of mortality as the ultimate boundary of any human life.

The third section, “Cures, Improvements, and Their Costs: Virtues for a Richer Bioethics,” moves from the anthropological questions to the ethical and spiritual ones, with special attention to human excellences that may be enhanced or threatened in the age of biotechnology. The three chapters in this section—“Vulnerability and Suffering,” “Living Immediately,” and “Human Dignity”—explore some of the deepest bioethical questions: the value, if any, of human suffering; the importance, for living well, of unmediated and direct engagement with the world and with our fellow creatures; and the character of human dignity. Once again, these are matters that tend to be neglected in current bioethical discussions. Yet on reflection, their centrality is not difficult to recognize, especially in such areas as our use of heroic measures to save and extend life, our increased reliance on psychotropic drugs to handle the trials and tribulations of life, or our attempts to describe and explain human life and human freedom solely in terms of genes, hormones, or neurotransmitters.

In the final chapter, “Human Dignity,” we turn explicitly to the theme that has been present tacitly throughout the volume and throughout all of the Council’s work to date: the dignity or worth or standing of the human creature. Although the term “human dignity” has a lofty ring, its content is quite difficult to define. To be more precise, different authors and traditions define it differently, as the readings in this chapter make abundantly clear. Yet they all are struggling to reveal that elusive core of our humanity, those special qualities that make us more than beasts yet less than gods. The encouragement and defense of the “human core” may be said, arguably, to be the highest mission of a richer bioethics.

The Council’s humanistic approach to bioethics, I am well aware, will be challenged, if not wholly dismissed, by some. We, ourselves, are cognizant of its shortcomings. Stories, however illuminating, are no substitute for argument and careful reflection. But I offer this challenge to all teachers of bioethics: design a course built around *Beyond Therapy* and *Being Human*, and see for yourself whether this approach does not produce

the liveliest, richest, and deepest discussions among your students and for yourselves.

*Reproduction and Responsibility:
The Regulation of New Biotechnologies*

From our first meeting, the Council has been interested in the subject of regulation. Bioethics commissions come and go. They take up important issues. They write reports. Sometimes, as in this case, their reports contain recommendations that may find a willing audience. But they have no oversight or regulatory authority. Their power consists only in their ability to persuade, and that is as it should be.

In this rapidly developing world of biotechnology, however, where the human import of the changes society is undergoing is hard to discover and where social institutions lag far behind in their ability to cope with the new challenges that innovations may bring, a strong case can be made for trying to devise suitable oversight and regulatory institutions and activities that could help protect society's basic values, even as we continue to treasure the benefits that biotechnology will continue to bring us. Legislation and prohibitions are suitable only for a few rare violations, such as human cloning, or euthanasia, or some of the prospects taken up in this Council report. Laissez-faire, although reflecting the honored American principles of freedom and choice, offers no guidance other than what the market will allow. Regulation would seem to offer a superior alternative, even if it is far from clear what form it should take or how it might be effected.

Following the release of its cloning report and in accordance with its own majority recommendations, the Council undertook a thoroughgoing enquiry into the current regulation of those intertwining biotechnologies that touch on human reproduction. *Reproduction and Responsibility* (PCBE 2004b) is the fruit of that enquiry. Its principal aim is to describe and critically assess the various oversight and regulatory measures that now govern the biotechnologies and practices at the intersection of assisted reproduction, human genetics, and human embryo research.

One cannot assess how well activities are monitored or regulated if one is unclear about which goods are in need of protection. In conducting its assessment, the Council identified numerous relevant goods, chief among them: (1) the health and well-being of the human subjects directly affected by these technologies, especially the children who may be born with their aid; (2) relief of the suffering and sorrow of those afflicted with infertility; (3) compassion for children with serious genetic diseases and relief of

the sorrows and burdens that they and those who love and care for them must bear; (4) the intrinsic value of new knowledge of human development and genetic function and the surpassing practical value of new treatments for diseases and disabilities; (5) the protection of reproductive freedom and the privacy of genetic information and reproductive practice; (6) the value of human life and the respect owed to it in its nascent stages; (7) the promotion of justice and equality, including equitable access to the use and benefits of new technologies, equal respect and opportunity in a world that places great emphasis on genetic distinctions, and the prevention of discrimination against or contempt for genetic “defectiveness” or “inferiority”; and (8) the protection of human dignity, including the dignity of the human body and its parts, the dignity of important human relationships (parent and child, one generation and the next), and the humanity of human procreation.

Reproduction and Responsibility systematically reviews all current regulatory activity, governmental and private, formal and informal, in these areas: assisted reproduction; screening and selecting for genetic conditions and traits (including sex selection); modification of traits and characteristics; research using *in vitro* human embryos; and commerce in and commodification of human reproductive practices. The extended diagnostic discussion makes clear precisely who currently provides oversight and guidance in each area, pursuant to what authority, according to what principles and values, and with what ultimate practical effect.

The Council finds that present regulatory institutions have not kept pace with the rapid technological advance. Although there is some existing regulation and some oversight in place, there are also great gaps. Indeed, there is currently no public authority responsible for monitoring or overseeing how these technologies make their way from the experimental to the clinical stage or how they affect the health and well-being of the women who use them or the children born with their aid. There is no authority, public or private, that monitors how preimplantation genetic diagnosis (PGD) or sex-selection technologies are being or will be used or that is responsible for attending to the ways they affect the health and well-being of the participants or the character of human reproduction more generally. Existing regulatory institutions, such as the Food and Drug Administration or local institutional review boards, do not at the present time oversee this area, and the welcome ethical standards promulgated by the professional societies are limited in scope and not binding on individual member practitioners.

Yet the Council has refrained, at least for the time being, from proposing major new regulatory institutions. Gaps in our current information make doing so premature, and our deep differences over the moral status of human embryos make it problematic. Before either policymakers or the public can address the need for institutional change, they first need more input from the relevant stakeholders and much more additional information. What are the true health effects of assisted reproductive technologies on children, mothers, and egg donors? Are assisted-reproduction patients able to make fully informed choices in the current environment? Could federal intervention be rendered unnecessary by better professional self-regulation? What would be the benefits and the costs of each of the proposed alternatives for expanding the responsibilities of current regulatory institutions or for designing new ones? The Council presents a series of recommendations—addressed both to government and to the relevant scientific and medical practitioners—for data gathering, reporting, and professional self-scrutiny. These recommendations are designed to help answer those and other such questions.

But even as we continue to look for suitable institutional reforms, the Council thinks that the nation would benefit from a series of targeted interim legislative measures that would safeguard certain important ethical boundaries. Seeking to contribute to that goal, Council members agreed to set aside for now those issues that deeply divide us—like the moral status of human embryos—and to seek instead a common moral ground. In what I take to be a major accomplishment, we have coalesced around principles that we all would like to see protected: preserving the reproductive boundary between the human and the nonhuman; respecting women and human pregnancy; respecting children born with the aid of the new technologies, securing for them the same rights and human attachments as other children enjoy; and respecting certain agreed-upon limits regarding the treatment of *ex vivo* human embryos.

Accordingly, the Council offers a series of modest yet precise legislative proposals targeting certain unethical or disquieting practices in human reproduction:

1. Prohibit the transfer, for any purpose, of any human embryo (produced *ex vivo*) into the body of any member of a nonhuman species.
2. Prohibit the production of a hybrid human-animal embryo by fertilization of human egg by animal sperm or of animal egg by human sperm.

3. Prohibit the transfer of a human embryo (produced *ex vivo*) to a woman's uterus for any purpose other than to attempt to produce a live-born child.
4. Prohibit attempts to conceive a child by any means other than the union of egg and sperm, by using gametes obtained from a human fetus or derived from human embryonic stem cells, or by fusing blastomeres from two or more embryos.
5. Prohibit the use of human embryos in research beyond a designated stage in their development (between 10 and 14 days after fertilization).
6. Prohibit the buying and selling or patenting of human organisms at any stage of development.

Based on our deliberations to date, we have reason to hope that these targeted measures will find support on all sides—pro-choice as well as pro-life, secular as well as religious, scientist as well as humanist, left as well as right. Like the nation at large, our members hold differing views about certain foundational questions, especially the moral standing of human embryos. Yet despite our great differences, we all support these proposals and urge their swift adoption.

The Council stands behind these recommendations unanimously, even though different members come to them from different premises and with different aims and hopes—as they articulate in their personal statements in the appendix to this document—and no member or the Council as a whole has had to recant positions taken in our previous cloning report. This discernment of practical common ground in the midst of meaningful disagreement is an accomplishment of which the Council is very proud. We hope it might point the way for others to seek and find the responsible way forward in this vexing arena of public policy.

GENERAL OBSERVATIONS AND CHALLENGES

So how, then, do we measure success or failure in this enterprise of ours? It is very hard to know. That many are firing at us, from both left and right, might be taken as a sign that we are having an impact, if only as an irritant. But, more seriously, it is possible to say something with regard to the specific functions that we were created to discharge.

Regarding our educational function and the goal of increasing public understanding, the record is mixed. If we are talking about educating policymakers, one thing I have learned in Washington is that it is very

hard to educate anyone about an issue unless you are prepared to tell them what they ought to do. Absent specific policy recommendations, busy legislators and government officials are not going to take the time to read lengthy reports and ponder. For this reason, I suspect that several of our projects have done little to advance public understanding in these narrow quarters. But regarding the wider public, I believe that the news is clearly much better. The Council's website is highly used. And three of our publications have been re-published by commercial publishers with the express goal of getting them into circulation for college and university teaching.⁶ Testing the educational value of these materials is, of course, partly up to readers of this journal: try them out; see if they do the job.

With respect to serving as a forum for national debate about bioethical issues, the Council has received an enormous amount of attention, and much ink has been spilled about us, most of it not on matters of substance. But we increasingly see references to our work, and the *Beyond Therapy* report in particular has stimulated a great deal of discussion on enhancement issues. In addition, we have contributed to a much wider public debate—about stem cell research or cloning or the regulation of biotechnologies—than occurred before we started our work.

On specific policy issues, we thus far have had no demonstrable effect. Our recommendations in the cloning report were not picked up legislatively. Yet it is too soon to tell what will happen to the recommendations from the *Reproduction and Responsibility* report: it was issued just as the 2004 election season shifted into high gear, and we must wait to see whether it can garner any legislative interest and support in the new Congress. I remain guardedly optimistic on this score. In other respects, I do believe that our work has been influential, for example, in encouraging various professional groups to re-examine and improve their own monitoring practices and tighten their own guidelines. Prodded in part by the attention we have given their activities over the past two years, the American Society for Reproductive Medicine has been revising several of its ethical positions and practice guidelines. In a most important new development, the Society has called for a significant reduction in the number of embryos transferred during IVF procedures, seeking to decrease the incidence of multiple births, the single largest cause of disability in the children born using assisted reproductive techniques (Practice Committee 2004).

Finally, concerning our charge to conduct fundamental enquiry into the human and ethical significance of biomedical advance, one must confess that such enquiry is hard to pursue with a fractious bunch of professors.

Yet I do think we have succeeded in enlarging the terms of the debate. And we have given much greater visibility to questions of the goodness of human ends and to questions about the character of the society that we are creating—and wish to create—with the aid of new biotechnologies.

This larger vision of the purpose of bioethics has been central to our work, and I hope it also will be our lasting legacy to the field. In the age of biotechnology, bioethics must do more than take up various techniques, and measure them to see if they might run afoul of beneficence, respect, and justice, and then move along. We have become quite good at noticing dangers to life, threats to freedom, risks of discrimination, signs of exploitation, and interference with the pursuit of pleasure. These are important, to be sure, but they are also the sorts of dangers that society is already very much “on alert” to avoid. Bioethics should attend to these, but it must also do us all the service of leaning against our modern inclinations and correcting for our excesses. This means that it must do much more than enforce a checklist of liberal shibboleths that need guarding. And it must offer more than an exchange of sanctimonious permission slips for unrestrained scientific freedom and technological innovation.

A proper bioethics must lead public reflection on the ways in which new biotechnologies may affect those things that matter most regarding how human lives are lived—things like family and friendship, childhood and parenthood, youth and old age, pride and humility, excellence and charitable love, and countless other crucial human intangibles that stand to be profoundly altered by new biotechnical powers. This means beginning by reflecting upon the highest human goods and understanding the latest technological advances in this light. It means practicing a truly humanistic bioethics enriched by the wisdom of the ages, suitably vitalized to inform the judgment of our democracy in an age of very complicated choices. It is this spirit, above all, that distinguishes our Council’s work, that informs the pages of every one of our reports, and that has defined the task we as a group have set out for ourselves.

I also hope that the future of public bioethics might learn something from the way in which this Council has viewed the relation between science and the political community, and especially the role of bioethical “experts.” For moral advice in dealing with sticky ethical issues, in recent years, biologists and biotechnologists have turned to bioethicists to help negotiate the difficult straits between science and society. Hospitals and biotech companies have hired them. Scientific societies retain them and the Human Genome Project has housed them handsomely under the tent

of big funding. And many bioethicists, for an honored seat at the conference tables and a share of the federal budget, have been only too glad to oblige. But it is not clear that society has been served adequately by this congenial compromise. For one thing, the arrangement has included only mainstream academic bioethicists, who are not representative of society as a whole. They largely share the scientists' moral outlook, a progressivist and Enlightenment view of the world, and a corporealist metaphysic. Most important, this arrangement suffers from an exaggerated view of the importance and sufficiency of expertise: scientific and technical expertise, on the one side, bioethical expertise, on the other.

Until our current bioethics Council, previous public bioethics deliberation was set up to produce a mixture of academic experts, scientific and ethical, with a feeble smattering of "public members." The goal, quite explicitly, was to shield these vexing and delicate subjects from the unwelcome intrusions of the noisy and contentious political process. These bodies have been very helpful, especially in devising regulations or refining practices. But because the bioethicists who have served on these bodies largely approve of whatever scientists propose to do, they will—after a suitable amount of hand-wringing—pronounce their moral blessings upon whatever practice is under review. But the price of this congenial relation is that official public bioethics has been insulated from the larger political culture where real and serious differences exist and where academic arguments of ethicists hold little sway. Worse, this attempt at government by experts has isolated the larger society from the opportunities and responsibilities of public decision making. Where biotechnology may be taking us is everyone's business. It is therefore fitting that the public should be involved.

The people who have accused our Council of politicizing science and bioethics have been right, but not in the way they meant. As I said earlier, we are a Council *on* bioethics, not a Council *of* bioethicists. We were constituted to reflect the large differences of opinion in the community at large. We have helped to bring important bioethical issues into the public arena, beyond the private domain of a small group of experts. We are proud of the fact that we eschew academic jargon, consider sensibilities as well as arguments, and welcome all perspectives—not just secular and liberal ones—into the public conversation. To be sure, in public discussion the experts have their role to play. But our ultimate arbiters of the right relations between science and society are the people and their representatives. For it is they—we—who are charged to think, act, and govern in this age of biotechnology in ways that will do full justice to our humanity.

The Council's task as a public bioethics body is as daunting as our ambition is high. The road is long and difficult. But I would like to think that we have made a useful start. The difficulties that certainly will confound further steps along this path are both practical and intellectual. Efforts to improve ethical oversight and develop workable regulatory practices and institutions of the sort that the Council has envisioned will run up against the nature of the American approach to regulation. We have little tradition for regulatory activities beyond matters of safety and effectiveness. We have a decentralized medical profession, rarely subject to scrutiny or guidance from above. We are wedded to the principles of freedom and *laissez faire*, and most people with a stake in biotechnology are deeply suspicious of and resistant to the idea of more governmental interference. And, finally, we face some truly intractable questions and issues: like Solomon's baby, the embryo question cannot be split down the middle.

Efforts to expand the scope of bioethical reflection, meanwhile, will likely be stifled first and foremost by the overwhelming predominance of "the life question" in our public considerations of bioethical topics. This has certainly been one of the most frustrating aspects of public bioethics as I have experienced it these past three years. All too often in public debate, bioethical controversy is fought out on the plane of what one may call the "the life principle," the principle that calls for protecting, preserving, and saving human life. The proponents of embryonic stem cell research argue vigorously and single-mindedly that stem cell research will save countless lives. The opponents of the research argue with equal vigor and single-mindedness that it would in the process destroy countless lives. As posed, it appears as an argument between two sorts of "vitalists" who differ only with respect to whose life matters most: the lives of sick children and adults facing risks of decay and premature death, or the lives of human embryos who must be directly destroyed in the process of harvesting their stem cells for research. Each side often acts as if it has the trumping argument: "Embryonic stem cell research will save the lives of people with diabetes or Parkinson's disease," versus "Embryonic stem cell research will kill tens of thousands of embryos." These are surely important—indeed, *crucially* important—concerns. But, at the risk of giving offense, I wish to suggest that concern for "life"—for its preciousness and its sanctity, whether adult or embryonic—is not the only important human good relevant to our deliberations. We are concerned also with human dignity, human freedom, and the vast array of human activities and institutions that keep human life human.

Important though it is, the “life principle” cannot continue to be the sole consideration in public bioethical discourse. Some efforts to prolong life may come at the price of its degradation, the unintended consequences of success at life-saving interventions. Other efforts to save lives might call for dubious or immoral means, while the battle against death itself—as if it were just one more disease—could undermine the belief that it matters less how long one lives than how well. At the beginning of life, certain modes of conceiving children—for example, by cloning—threaten human dignity, even if no embryonic lives should be lost in the process. And, in extreme circumstances, perhaps, lives may even need to be risked or even sacrificed so that the community might survive and flourish. Such questions of the good life—of humanization and dehumanization—are of paramount importance to the field of bioethics and to the future of our nation and the human race.

NOTES

1. For a compelling account of how public bioethical discourse became so thin and narrow, see John H. Evans’s excellent book, *Playing God? Human Genetic Engineering and the Rationalization of Public Bioethical Debate* (2002).
2. Rebecca Dresser, William F. May, Gilbert Meilaender, and I.
3. The Dickey-Wicker Amendment, added to the Balanced Budget Downpayment Act (Public Law No. 104–99, Title I. Sec. 128, 110 Stat. 26, 34 (1996)), has been enacted annually by Congress since 1996 and has been signed by both Presidents Clinton and Bush.
4. Thoughtless people, including, I regret to say, some prominent bioethicists, have poked fun at the Council’s occasional use of literary materials in its meetings and writing. But if we are adequately to appreciate the “human and moral significance” of biomedical advance, we would be foolish to ignore the insights of great thinkers and poets, dead as well as living, and rather to rely solely on the writings of academic bioethicists. Should we really try to grapple with whatever might be humanly and ethically significant by excluding from our resources the best that has been thought and said?
5. Because the Council was unable to reprint *Being Human: Readings from the President’s Council on Bioethics* after the first edition, we are pleased that W. W. Norton (2004) has re-published the volume in its college editions series, under the altered title, *Being Human: Core Readings in the Humanities*.
6. Public Affairs has published *Human Cloning and Human Dignity: The Report of the President’s Council on Bioethics* (2002); Regan Books (2003) and Dana Press (2003) have each produced a new edition of *Beyond Therapy:*

Biotechnology and the Pursuit of Happiness; and W. W. Norton has re-published *Being Human: Core Readings in the Humanities* (2004).

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