



FROM BIRTH TO DEATH AND BENCH TO CLINIC

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for Journalists, Policymakers, and Campaigns

INTRODUCTION

Bioethics and Policy—A History

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Bioethics and Policy— *A History*

BY DANIEL CALLAHAN

COFOUNDER, *THE HASTINGS CENTER*

The word “ethics” makes many people nervous. It can connote religious or ideological dogmatism, with hard-nose rules about right and wrong. Or it can mean an endless quest to determine just what is right or wrong—a quest uselessly mired in 2,500 years of disagreement. Yet whatever one perceives ethics to be, it is impossible to escape dealing with it. We have to ask how best to direct our personal lives, how best to live with other people, and how best to organize and manage our society. For Aristotle, ethics was a branch of politics, and politics needs to be rooted in some notion of the common good and the need to develop assorted laws, policies, and other means to regulate society.

It has been said that, in stable times, one hardly has to think of ethics at all. Rules for living our private lives and living together with others are settled and taken for granted. A worry about ethics typically emerges when serious political, scientific, and cultural changes are afoot. That was exactly the case with the emergence of bioethics. Prior to the 1960s, medical ethics was mainly in the hands of physicians. It had scarcely changed from the ancient Hippocratic tradition and focused almost exclusively on the welfare of patients and medical professionalism.

By the 1960s, however, a wide range of new ethical problems came rushing into view, all of them driven by spectacular advances in medicine and biology. The old medical ethics could not contain their scope and variety: new genetic knowledge, contraception and safe abortion, organ transplantation, a new definition of death, sophisticated ways to keep people alive (often too long), the first signs of anxiety about health care costs, and a more edu-

cated public that was less willing to accept “doctor knows best” physician paternalism. The issues were moving well beyond the boundaries of the old medical ethics, and the word bioethics was coined to capture that rich complexity.

From the first it was understood that bioethics had to cast a wide net, moving from the most intimate doctor-patient encounters at the bedside to the most public kinds of decisions on the provision of health care. Good ethics in that context meant working at both ends of a spectrum: a serious grappling with basic issues of human nature, rights, and dignity—where should medicine be taking us?—and dealing with the most practical of policy matters. The latter meant the fashioning of regulations for the allocation of, say, scarce organs for transplantation, or determining appropriate rules for terminating treatment of a dying patient. It soon came to mean, as well, the fairest way of organizing a health care system and paying for ever more expensive medical care.

That attempt to work through the full spectrum of issues has had to cope with an understandable but troublesome tendency in our public discourse: the larger and more fundamental human questions that should be engaged are put aside, and the focus is mainly on those issues that lend themselves to some concrete legal or legislative outcomes acceptable in a pluralistic society. The cases the United States Supreme Court chooses to hear are illustrative of the problem. The Supreme Court reportedly tries hard to avoid taking on questions at the basic constitutional level, preferring that as many issues as possible be dealt with by lower courts. The Court has long understood that the more basic the issue, the more divisive it will be.

Something similar happens with public policy debates, which are not known for comfortably taking on deep problems of social philosophy. Bioethics is willing to engage in such debates. But it recognizes that, with policy issues, action is ordinarily what is desired, and of a very specific kind—such as rules to regulate human subject research. While bioethics must speak to that dimension, the historical uniqueness of so many of the pertinent issues do not allow for too sharp a distinction between the different philosophical and political levels of analysis. To establish good law for the definition of death, for example, it was necessary to ask some profound philosophical questions. What is it about a person that separates him from the living or the dead: his intact, working brain, or the functioning of all his major organs? Would it be for or against our notions of human dignity to allow life-saving organs be sold, or would it be likely that only the poor would be willing to sell them?

Bioethics and Health Care Reform

The present debate on health care reform, which is of great current relevance, can be understood at both these levels of analysis. At a particular level, it can be considered as only a matter of more cleverly organizing and managing our health care system. What kinds of administrative and other arrangements will make it work better? If the main problem is understood simply as one of poor efficiency and needless waste, that might work well enough. However, our present debate encompasses larger questions: What would constitute the most equitable system for those who can not afford care? That elevates it to a philosophical struggle between those oriented in favor of a market-biased system, heavy on the private provision of care, or a government-biased one, aimed at collective benefits. With matters of that kind, ethics does become a branch of politics.

The problem becomes all the tougher when efforts must be made to cut health care costs. Who should bear the brunt of those efforts, which will be painful? The idea of treatment based on “medical necessity” is at the core of both our public and private care, but the concept of necessity is one with very different ethical meanings. Expensive care at the end of life—when death is surely on its way but perhaps open to being extended a few more months—is necessary if one believes everything should be done for a patient regardless of

cost. It is enormously more complicated when it is understood that, if the notion of necessity is not allowed to take account of costs, then other patients with better prospects may be deprived of the care they need.

Medical research and technology are changing our lives in dramatic ways. We live longer and in better health, and there is more we can do to raise healthy children and care for our elderly parents. But few of these advances come with problem-free outcomes. There are difficult ethical and policy dilemmas in caring for critically ill newborns, and no less so with the care of those with Alzheimer disease—a rapidly growing number, in great part precisely because we are living long enough to get such a disease. We call problems of that kind the dilemmas of success! The genetic possibilities for shaping our children are both exciting and fearsome. Do we really know what would be best for our children?

For years it has been said that we have a sick care system, not a health care system. That is because we place disproportionate emphasis on getting cured when we get sick, and far less on avoiding sickness in the first place through prevention. Increasingly though, prevention must have its day. But successful prevention efforts require more than lectures against smoking and bad diets. They will mean changes in the way we and our children live our daily lives: more exercise, more sidewalks, and more public transportation. Yet we have few good ideas in our society about how to bring about the kind of social change which is outside of the medical realm but has just as great an impact on our health as medical care. The best predictor for a long life is a long education, but health policy and education policy are only rarely joined or thought about together.

Bioethics can hardly solve those problems by itself. But because of the unique way it brings ethical and policy issues together, it has some special contributions to make. It asks questions and pursues solutions in ways different from much policy analysis. It can touch our lives at their deepest points, when life and death issues must be confronted. It can no less touch us in our daily lives, working to keep us healthy in ethical ways, yet also knowing when the quest for health becomes disproportionate in comparison with other pressing national needs. Bioethics is about 40 years old. It still has much to learn and much to give.