MIDWEST MEDICAL ETHICS

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CENTER NOTES

One of the major projects undertaken this year by the Center has been the establishment of an Ethics Committee Consortium. With the help of a planning committee, the consortium has established as its primary mission support of ongoing development in each institution of an ethics committee that will meet the needs of that institution.

The consortium plans to achieve its goals primarily through educational programs. In June the Center and the Consortium presented a day-long workshop for ethics committee chairpersons. The program included presentations on the challenges facing multi-disciplinary ethics committees; the importance of establishing and maintaining a strong relationship between an ethics committee and its institutional base; and techniques of conflict resolution.

In addition to its educational function, the Consortium hopes to play a role in networking of area ethics committees. At an upcoming meeting the members will share information regarding the efforts of member institutions to forego the use of resuscitative technologies (so called DNR orders).

The Consortium is also planning to undertake community service projects on a limited basis. Under consideration at this time is a program to assist the community in developing policies for honoring DNR decisions.

The consortium is open to hospitals, nursing homes, and other health care groups who are institutional members of the Midwest Bioethics Center and who have an ethics committee.

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Board Member

Congress Forms Biomedical Ethics Board

by Albert Gore Jr.

Introduction

Making public policy is fast becoming a more difficult and more sensitive challenge. There is an overwhelming amount of information that should be considered before any policy is formulated. Consequently, it behooves those of us in Congress to obtain all the information we need to make policy. Like a Court whose decisions must often turn on special technical knowledge, so we must decide on policies whose rightness or wrongness turn on certain facts. To this end courts bring in expert witnesses, and we hold hearings. But sometimes we need answers to specific questions, answers not yet available. To meet that need we chartered the National Academy of Sciences in 1863 and, much more recently, established the Office of Technology Assessment. Through these groups we can expect to get relevant and objective facts. Both NAS and OTA are noted for being thorough and non-partisan. To make policy, at the very least we must agree on a body of facts apart from political considerations.

Ethics presents us with an analogous situation. More and more we are forced to make policy on matters which involve ethical assumptions, ethical implications, or ethical dilemmas. These ethical matters need to be objectively focused, described, and discussed. And recommendations need to be made which represent the best non-partisan, objective, and consensual agreement that can be achieved. As with the scientific and technological facts, this activity should be an enterprise unto itself. It should take place apart from policy deliberations, and it should clarify the value framework within which policy is argued and formulated. It should articulate the relevant ethical assumptions, implications, pitfalls, and positions. To provide a forum and mechanism for this activity, I sponsored legislation which became law in 1985 to establish the Biomedical Ethics Board.

The Legislation

The Board is, in a sense, modeled on the Office of Technology Assessment. Its members include both Representatives and Senators and its function is to discover, study, and report. It has no legislative authority. More specifically, the Board studies and reports to Congress on a continuing basis "the ethical issues arising from the delivery of health care and biomedical and behavioral research, including the protection of human subjects of such research and developments in genetic engineering (including activities in recombinant DNA technology) which have implications for human genetic engineering." (Public Law 9-158;

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On the Inside

Legal Update

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Beverly Requena was admitted to Riverside Hospital in Boonton, New Jersey, in April, 1985, just after a diagnosis of amyotrophic lateral sclerosis (ALS). She has been on a respirator ever since. That fall, Riverside and St. Clare's Hospital merged into a new entity, run by an order of Roman Catholic sisters. When Mrs. Requena decided that she would refuse to accept feeding by artificial means after her ability to swallow was gone but refused to leave the hospital despite the hospital's policy of requiring such feeding, St. Clare's/Riverside brought suit to have her removed.

The court first detailed Mrs. Requena's condition: fully conscious and alert but unable to move any part of her body except facial muscles. Her decision to refuse artificial feeding was one of long standing, carefully considered, and was accepted by her treating physicians and family. While the treatment she desired was available at another nearby facility, she did not want to suffer the emotional upset of leaving the staff in whom she had trust and affection.

Balanced against these concerns were the staff's right to refuse to participate in Mrs. Requena's requested treatment and the stress they would experience in being forced to do so. Noting that the staff were strong, healthy people who could withstand the situation, while their patient assuredly would not, the court determined simply that it was "fairer" to ask them to give than to ask their patient.

The court presented a sensitive, moving discussion of the conflicting rights and concerns in this case. It distinguished the case from the abortion issue and from suicide. It distinguished artificial feeding from "medical treatment." It made a case for including the treting physician in ethical policy-making decisions and appealed to hospital authorities to withhold a judgmental attitude in their care of "this most needful sister of ours."

In Re Requena, 517 A.2d 886 (N.J. Super. Ch. 1986)

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Board

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November 20, 1985) The Board must also submit an annual report to Congress. The report, in addition to identifying what issues were studied, will identify "areas, programs, and practices of medicine and biomedical and behavioral research which have significant ethical implications and which would be appropriate subjects for study." (ibid.)

Several issues have been given priority on the Board's agenda by the law itself. The first item on the agenda is a report on research and developments in genetic engineering (including developments in recombinant DNA technology) which have implications for human genetic engineering. Next on the agenda is fetal research. Fetal research is currently severely restricted. There is, however, a provision that allows for modifying or waiving specific requirements under special conditions. (Title 45, Code of Federal Regulations, Part 46.211) The charge to the Biomedical Ethics Board is to study the nature, advisability, and biomedical and ethical implications of exercising any waiver of the risk standard. And the risk standard that is to be considered by the Board is that of "minimum risk". ("Minimum risk" means risks no greater in probability and magnitude than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.)

One could reasonably speculate that other issues should be looked at by the Board. For example, recent events will force us to consider issues of reproductive technologies. The Baby M case of surrogate motherhood and the Vatican's recent "Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation" both dramatically bring these concerns into public discussion. A gamut of opinions, stances, uncertainties and confusions is being unleashed. It would seem to be an entirely appropriate matter for the Board to consider. But any addition to the agenda must be approved by the entire Board. As of this writing, the Board has not met to set agenda.

There is one more crucial aspect to the law establishing the Board. That aspect is the Biomedical Ethics Advisory Committee, which will really be the working arm of the Board. It is the Committee that will conduct the studies and make the reports legally required of the Board. The Committee may also hold whatever hearings and take whatever testimony it considers appropriate to carry out its assignments.

> "The first item on the agenda is . . . genetic engineering."

The Advisory Committee will be composed of fourteen members from outside the federal government. Specifically, there will be four members from biomedical or behavioral research, three from health care providers, five from such fields as ethics, law, humanities, health administration, public affairs, etc., and two "laymen" who have no particular expertise, but who in some sense represent the general citizenry. All these persons should be distinguished in their fields. It is not that only "distinguished" persons can fruitfully deliberate about these issues, but it is important that those who are representatively doing so be widely known and trusted as thinkers and statesmen in their respective disciplines. These fourteen will be selected by the members of the Board from a slate of nominees also generated by the Board members.

Current Status

The members of the Board, in accord with the law, are six senators and six representatives, and their numbers are evenly divided between the two parties. The Board selects a chairman and a vice chairman from among its members at the beginning of each Congress. Furthermore, the chairmanship and vice chairmanship

alternate between the Senate and the House with each Congress (that is, every two years) and the chairman and vice chairman must not be from the same House of Congress at the same time. (That is, if the chairman is from the Senate, the vice chairman must be from the House of Representatives, and visa versa.) In the last Congress (the 99th) Senator Lowell Weicker (R-CT) was the chairman, and Representative Willis Gradison (R-OH) was the vice chairman. At the beginning of the 100th Congress Representative Gradison was selected as chairman, and I was selected as vice chairman.

Other current members of the Board are Representatives Thomas Bliley (R-VA), Thomas Luken (D-OH), Roy Rowland (D-GA), Thomas Tauke (R-IA), Henry Waxman (D-CA) and Senators Dale Bumpers (D-AR), David Durenberger (R-MN), Gordon Humphrey (R-NH), Edward Kennedy (D-MA), and Lowell Weicker (R-CT).

The Advisory Committee has yet to be appointed. Establishing the committee is our first order of business; the process has been underway for several months. As one might imagine, narrowing down the very large number of qualified candidates is an enormously difficult task. We receive consultation from objective and knowledgeable sources, though ultimately the Committee is appointed by the Board. Once the Committee is in place we will move quickly to determine our agenda and to begin our studies.

Ethics, Politics, and Consensus

This descriptive article is not the place to pursue the conceptual aspects of our congressional board. But those aspects are certainly among the most interesting, especially to readers of this publication. It may be worthwhile to conclude this article by raising questions dealing with those matters in the hopes of stimulating and focusing thoughts on these more philosophical issues.

1. Consider the nature of the Advisory Committee. Should all the members be ethicists — either professional ethicists or professionals with an ethics avocation? What is an appropriate "balance" for the committee? Was it proper that there was no mention in the legislation of ethical points of view which ought to be represented? Would it make sense, theoretically speaking, to have a "moral balance"? What would be the assumptions of a "yes" or "no" answer to that question? The disciplines to be represented on the Committee are specified by the legislation in order to achieve a balance of expertise. This must assume that there are no ethical biases attached to particular disciplines. Does it also suggest that knowing the facts is more crucial than being knowledgeable about ethics? Or is it expected that everyone is a moral agent and that the level of expertise in ethics need not be great, as long as the facts of the situation are clearly known?

"Our deepest emotions and values seem to be under challenge, particularly by the new biotechnology."

2. Should there even be an ethics board at the highest levels of government? Might morality end up being legislated? Should it be? On the one hand, public policies inevitably take stands on moral matters; they could hardly do otherwise since policies affect people in crucial ways. But on the other hand, moral matters are frequently regarded as highly subjective and hence one person's morals should not become another's law. One would expect this dilemma to be resolved by finding important distinctions between those values which are subjective and those which we in some sense would or should share — at least, that rational people would or should share. Thus the former, which we might call philosophies of life, could not be legislated, but the latter, insofar as they are universal and crucial to our mutual survival, could be. Knowing the difference, if there is one, would be central.

3. Another reason why an ethics board at a national level might be important is as a place to "settle" moral issues. That is, there are many issues in the "moral" domain which do not really admit of a right or a wrong answer. (At least so I would contend.) These are issues on which equally moral and rational persons might disagree. Consequently a national consensus is needed. We need a forum for looking at the facts and the arguments and then making a decision as to what will be declared the standard of practice.

4. There is one value that we all share — individual liberty. But why then do we have a Board which might lead to restraining freedom in experimentation, research, therapies, opportunities, etc.? Surely the burden of proof is on whoever would take away that personal freedom. But there are often reasons which outweigh the presumption of freedom. These reasons generally have to do with the balance of harm done if the restraint is not imposed. The matters to be dealt with by our Board have the potential for enormous harm and enormous good, and they are matters about which persons have deep emotions. So it is quite conceivable that some legislation will be in order, though only as much as necessary to accomplish the benefits while minimizing the risks and harms.

Our deepest emotions and values seem to be under challenge, particularly by the new biotechnology. We need careful analysis of those emotions and values and also of the biotechnology in order to see wherein the challenges are real and wherein they are not. Insofar as they are real, we must meet them. There is no avoiding them; they are upon us. If our Board becomes the forum for fashioning a national consensus, it will have fulfilled a large part of its purpose.

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