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9

Just Caring

An Experiment in Health Policy Formation

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Over the past three years or so, a movement has gradually developed that is described as the “Health Decisions” movement. It refers to statewide, grass roots efforts aimed at stimulating health policy discussions at the community level about many of the more controversial and morally troubling aspects of health policy in the United States. This is an important social and political phenomenon for four reasons. First, these projects have attempted *not* to be just another special interest group in the state. Rather, they have aimed, through public conversation, to identify *common* purposes in health decisions. In analyzing these projects, Bruce Jennings writes that “they have taken pains to avoid polarizing the issues with which they deal. Their objective is to provide a new space for moral and political discourse. This is the space of the democratic forum, where groups that usually confront one another in an adversarial fashion can bracket their differences, at least for a while, and search for common objectives and some common ground. The guiding metaphor of these projects is conversation, not confrontation; and their spirit of advocacy is tempered by one of open and tolerant inquiry” (Jennings 1988, p. 9). This attitude of open and tolerant inquiry should be seen as motivating the project I describe later in this essay.

Second, these projects help to disabuse us of the false belief that our moral concerns and moral conflicts are purely matters of private conscience to be worked out however we wish within that personal inner sanctum. This is especially true when the moral value with which we are concerned is that of justice. If justice exists anywhere, it must exist as a feature of our social policies and practices, not our private consciences. As the philosopher John Rawls observes, “Justice is the first

virtue of social institutions, as truth is of systems of thought'' (Rawls 1971, p. 3). Just as truth must be an object of public inquiry through the methods of science, so also justice must be an object of rational public inquiry. The difference is that we have had good models of how science ought to be carried on for the past 400 years. We have had few good models of how public moral inquiry might be done, though the objective of these projects is to create such models.

Third, these projects are important because they reinforce the idea that profoundly moral issues in our public life ought not to be left to political and moral experts, much less managerial, organizational, or economic experts. As Daniel Callahan has noted, there is a strong temptation in our society to treat the problems of health care financing, health care cost containment, and health care rationing as exclusively economic and organizational issues, ignoring entirely the moral dimensions of these issues (Callahan 1990, p. 27). There are reasons why this happens, but they are not good reasons. The issues that need to be addressed are potentially painful and divisive. Health policy options that require us to consider who lives, who dies, and how much we as a society are willing to spend to save or prolong a life are difficult choices. Our social life will be much more pleasant if we can continue to affirm the social illusion that human life is priceless. And, of course, we can get away with just that if we give authority to economic experts to make these choices in think tanks safely sequestered from public view. However, making appropriate decisions in these matters is a moral responsibility that each and every citizen has; and hence, a good democratic society will provide democratic forums and decisionmaking structures that will facilitate the carrying out of that responsibility by its citizens, even though the matters to be discussed are painful and divisive. The fact is that health policy decisions do affect all of us, not just economically, but in profoundly moral ways. *The choices we make with respect to health policy reflect very concretely the extent to which we are a just and caring community in practice.* Symbolic social affirmations of the pricelessness of human life that mask discriminatory rationing decisions privately effected are both dishonest and unjust.

Fourth, if there are limits to what we can and ought to spend on health care as a social good, and if the factors that have precipitated escalating

health care costs over the past 20 years are going to continue unabated and even intensified for the foreseeable future, then we will have to accept the conclusion of most health economists that rationing access to health care is inescapable (Fuchs 1974, chap. 1; Thurow 1985, pp. 611-14; Schwartz 1987, pp. 220-24). But, I would argue, we ought not accept the conclusion, advocated by some,¹ that such rationing be effected by institutional mechanisms that are private and invisible, hidden from public scrutiny. I have argued elsewhere that such invisible rationing mechanisms are presumptively unjust.² Just rationing policies can be effected publicly. Again, the virtue of the Health Decisions movement is that it has provided us with models of how such public conversations can be productively carried on. It has helped to make these choices visible, painful and tragic though they be.

Though the state projects that have come under the rubric of the Health Decisions movement have had much to recommend them, there has been one major shortcoming. It is that most of these projects have been organized around discrete public forums and workshops that have attempted to address “the” problem of escalating health care costs and equitable access to health care. In point of fact, however, there are at least 20 large problems that can and ought to be distinguished within this policy domain. What virtually everyone who is familiar with this problem domain concedes is that multiple, conflicting social and moral values are at stake, and that tradeoffs need to be made. This last point is something that the larger public will never achieve an adequate appreciation of, so long as their exposure to these issues is in discrete chunks. More sustained and comprehensive public conversations that span months and years are needed to bring about that level of public understanding. What we describe below is a project that represents one model of how that might be done.

In these introductory remarks, I have made what some would regard as debatable assertions which really are in need of intellectual justification, since they ground the practical need for the project I describe. One such proposition is that health care ought to be thought of as a *social* good or public good rather than simply a private consumer good that is properly distributed according to individual ability to pay. This proposition is needed to support the moral claim that there are matters of

justice that need to be addressed as part of our choice of health care policies. My second claim is that there are multiple moral problems connected with justice and health policy that need to be addressed and that require, for their resolution, value tradeoffs. During the 1970s, philosophers seemed to think there was really only one moral issue here, namely, whether or not there was something called a right to health care. Anyone familiar with health policy today in its concrete details would see that as a wholly inadequate moral framing of our problem. In the first part of this essay, I attempt to provide a sketch of an intellectual justification for these claims. In the second part, I describe a model for a statewide project that would address, through public conversation, the moral issues that are integral to our health policy choices at both the state and national levels.

Health Care Justice

Who Lives? Who Pays? Who Cares?

The current climate in health care is dominated by multiple demands for health care cost containment. These demands come from both the public and private sectors. The statistics cited most often to portray the problem are the following: In 1990, it is estimated that we in the United States spent about \$660 billion on health care, which represented about 12.2 percent of our Gross National Product (GNP). By way of comparison, in 1960 we spent \$26 billion on health care, which represented 5.2 percent of GNP then. While the dollar figures are very large, what is most distressing to economists and policymakers is that the fraction of GNP devoted to health care has more than doubled. Worse still, there are few signs in the foreseeable future that escalating health costs will flatten out. Over the past 20 years, health costs have escalated at roughly twice the rate of inflation as measured by the Consumer Price Index, and this has remained true through a major recession during the 1980s and assorted stringent efforts at health care cost containment. Again, by way of comparison, Great Britain spent about 6.4 percent of its GNP on health care in 1989, while Canada spent about 8.7 percent of its GNP. The implication here is that it is possible to spend less on health care;

and, at least in the case of Canada, to have a health care system equal in quality to what we have in the United States (Evans 1986; Evans et al. 1989).

If health care were purchased as a private consumer good, as are all sorts of other consumer goods, then all of the above statistics would have little practical import. For they would simply reflect in aggregated form hundreds of millions of individual consumer decisions to purchase health care rather than something else. However, we do not treat health care as a private good. Rather, since the 1930s we have treated it as a social good, which is purchased primarily through an insurance mechanism, either in the private sector or the public sector. No one doubts that health insurance represents a rational social response to the personal tragedy of serious illness and hospitalization. For the fact is that the occurrence of illness for any individual is mostly unpredictable. Further, in the case of serious illness, there will usually be high costs associated with either cure or relief of the illness, costs that few people would be prepared to meet. It was no coincidence that *effective* health care and health insurance emerged about the same time. What we mean by “effective” health care are interventions that saved lives, prolonged lives, and relieved serious suffering. These are goods to which *all of us* want and need secure access, most especially when we are ill. Health insurance represents one sort of appropriate social response to that need.

While there may be much that individuals can do to forestall the occurrence of many diseases, there is relatively little that individuals can do *as individuals* in response to serious disease once they have been afflicted with that disease. Again, a rational approach to this problem is to devise appropriate *social* responses. Thus, the bulk of medical research and medical education are publicly funded. Physicians have the healing powers they have because a large social investment has been made in them. Moreover, public dollars have built most of the hospitals and paid for most of the technology that makes our health care system effective. As a society, we have even facilitated the purchase of health insurance by exempting that benefit from income and social security taxes, which represented a \$48 billion subsidy to the middle class and \$48 billion in revenue forgone by the federal government in 1990. It

would be very difficult to justify this kind of subsidy, either morally or politically, if what were being publicly subsidized were simply private expenditures by the middle class.

Everything said thus far may be taken as so much stage setting for our primary claim, namely, that there are profound *moral* issues that must be addressed as we make appropriate health policy decisions. For example, in arguing that health care represents a *social good* in our society, what we are implying is that there are important matters of justice pertaining to how this good is distributed, which would not be the case if it were merely another private consumer good. Thus, no one objects to the fact that a unique Picasso painting is sold to the highest bidder, but virtually everyone in our society would be morally outraged if human hearts or livers for transplant purposes were literally auctioned off to the highest bidder. This seems like a solid moral intuition on which there is widespread agreement. But it does not seem to take us very far. If the wealthiest individual with a failing heart or liver has no special moral claim to that organ, who does and who is to decide?

We often think of our society as being meritocratic, which suggests that there are always some individuals who are “more deserving” than others. This makes sense when we are thinking about rewarding individuals for a job well done with a promotion or pay raise. But how would such notions apply when we are distributing transplant organs, which literally will make the difference between life and death. Some may be tempted to suggest that there are individuals who have contributed more to society than others; but certainly this is the sort of claim that could be open to interminable dispute about how we would judge and compare an indefinite variety of incommensurable social contributions. Moreover, many would feel that there was something morally inappropriate and incommensurate in “rewarding” some productive individuals with life while consigning others who were a bit less productive to death.

For those who are inclined to some sort of egalitarian conception of justice, it might seem that because we all have an equal right to life, all who need that organ transplant should at least have an equal chance to get it. This idea has considerable moral appeal. However, the Pittsburgh transplant surgeon Starzl drew significant criticism when he did

a liver transplant in 1987 on a 76-year old woman (Koenig 1986). After all, he could have saved more life-years at a lower cost per life-year if a younger patient had received that transplant. This erodes a bit of our confidence in the egalitarian ideal. Then, of course, there are all those patients whose livers or hearts are failing because of their own bad health habits, i.e., an alcoholism problem, or cigarette smoking, or poorly managed stress, etc. Many would feel it is unfair if these individuals have an equal claim to a transplant organ when others have done nothing to bring an organ-destroying illness upon themselves. Most recently, the question was raised of whether individuals who are seropositive for the AIDS virus should have an equal right of access to an organ transplant. It needs to be noted that such individuals will more than likely go on to have the full-blown version of AIDS, from which they will die. However, it could be as long as 10 years before the disease actually manifests itself. In the meantime, this individual has an immediate need for that life-preserving organ transplant.

Nothing said here is meant to suggest there is any easy or obvious answer to these moral problems. There are conflicting intuitions of justice in these cases that pull us (both as individuals and as a society) in various directions. To make matters even more difficult, we need to note that justice is not the only moral value at stake. Many in our society would assert the equal moral importance of affirming the "pricelessness of human life." This value represented "cheap and easy" morality when there was relatively little that medicine could do to prolong human lives afflicted with life-threatening disease. But in an era of rapidly proliferating, expensive, life-prolonging medical technologies, sustaining this value is neither cheap nor easy. And in the real world it often represents a threat to our commitment to justice.

A clear example of how the pricelessness ideal threatens justice is to be found in the Cruzan case in Missouri. Nancy Cruzan was a 25-year old woman in 1983 who was involved in an automobile accident that resulted in her being reduced to a persistent vegetative state for the next seven years. She was sustained in this unconscious state via tube feedings, which her parents asked to have discontinued so that she be allowed to die. Virtually all of the attention of the public and the courts was focused on the issue of whether surrogate decisionmakers have the

moral right to choose death for an incompetent patient. But what was ignored was the equally significant moral issue raised by the fact that the State of Missouri was paying \$130,000 per year through Medicaid to sustain Nancy Cruzan in that unconscious state, this in keeping with its recently enacted “right-to-life” constitutional amendment. What makes this a significant issue of justice is that the Missouri Medicaid program covers only 40 percent of those below the poverty level, and clearly those other 60 percent could benefit much more from secure access to health care than Nancy Cruzan.³

But even if we ignore for a moment these conflicts between justice and the pricelessness ideal, there are substantial difficulties in interpreting what that ideal itself is supposed to mean practically. One way of interpreting what is meant by the pricelessness of human life is to say that a good society will not allow people to die who cannot afford the successful but expensive medical technology that might save and prolong their lives. Our commitment to this belief is most clearly illustrated by the 1972 Medicare amendments that underwrote the cost of dialysis for all those with renal failure. (Prior to those amendments the cost of dialysis, at \$30,000 per year in 1968, was a real barrier to access for the vast majority of patients in that condition. Further, there was only one dialysis slot available for every ten patients who needed a slot for survival.) As a result of those Medicare amendments, there are 95,000 people alive today who owe their life to that program. But the cost of that program to Medicare in 1988 was about \$2.8 billion. Further, Congress has, of late, strongly resisted any effort to create a similar program that would underwrite the costs of organ transplants, now with a much higher success rate as a result of the introduction of (expensive) immuno-suppressive drugs such as cyclosporine. Major transplant surgery generally carries front-end costs of \$100,000 to \$150,000 per case. What should we conclude from this lack of political enthusiasm? Do we value human life less now? That is, do we no longer think human life is priceless? If so, should we be subjected to moral criticism? What does justice require in these circumstances so far as our health policy is concerned? Are we treating those in need of organ transplants unfairly, since we refuse to provide public funding for these procedures, especially when we consider that those in need of organ

transplants have paid taxes to fund renal dialysis? And what are we to conclude, morally speaking, about the fact that we do fund kidney transplants through the End-Stage Renal Dialysis (ESRD) amendments, but not other organ transplants?

It was announced in October 1987 that the federal government had awarded the University of Utah a \$10 million grant over a five-year period to finish the development of a totally implantable artificial heart (TIAH). Unlike the artificial heart that sustained Barney Clark for several months, this heart would not require a 300-pound power source outside the individual. Its power source would be wholly self-contained. On the assumption that this project is successful, how should we respond from a moral perspective? Such a device might be able to prolong the lives of more than a hundred thousand people each year who are in the end stages of heart disease. But the cost of implanting that device in all those people would be more than \$12 billion per year, unless we were able to agree upon some set of criteria for rationing access to that device. Here we need to keep in mind that an advantage of the limited supply of natural hearts for transplant purposes is that we cannot escape the need to make rationing decisions. But if we arbitrarily limit the number of artificial heart transplants for political or economic reasons, then we will be saying publicly that there are some lives that *we judge are not worth saving*, even though we have the technology available that could save those lives. That would represent a public repudiation of the widely held belief that human life should be thought of as being priceless. Further, there would be intense public conflict over what represented a truly just distribution of the artificial hearts that were available. At the moment, the choice is still theoretically available to us as to whether or not we ought to fund such technologies. Would we be unjust as a society if we were to choose not to fund that technology?

It would be a mistake to think that the problems we are sketching here pertain primarily to organ transplants. The larger issue pertains to what our societal response ought to be to the occurrence of catastrophic illness. As the health economist, Victor Fuchs, points out, health insurance was originally designed to protect all of us from financial ruin by spreading out the risk associated with costly catastrophic illness.

The assumption behind such insurance is that relatively few people would be so afflicted. However, given the continued advances in life-prolonging technology of all sorts, the likelihood is that the vast majority of us will be afflicted with one or more costly episodes of catastrophic illness. That threatens to undermine the whole point of health insurance. The response of insurance companies, as they seek to protect their own interests and those of their clients, has been to increase their vigilance in identifying before the fact individuals who are most likely to suffer such catastrophic illnesses. The best current example would be individuals who are sero-positive for the AIDS virus. Those individuals are then denied insurance, which will mean that they will ultimately be denied needed health care.⁴

The average heterosexual reader should take small comfort in knowing this because, as more tests are developed to identify individuals who are genetically predisposed from birth for certain illnesses, those individuals too will be excluded from insurance pools. It is easy enough to understand the reasoning of insurers in these matters: they will argue that they are not a welfare system, but a mechanism for distributing risk. Still, the net result will be that those who are most in need of health care will most likely be denied access to the health care that they need. This result seems neither just nor humane. But it is clear that this is the direction in which we are moving. Further, where we could once expect that community hospitals would care for these patients as charity care, that is becoming increasingly less true. Hospitals find themselves under intense pressure from purchasers of their services to give discounts, and that effectively eliminates the financial cushion that permitted hospitals in the past to provide charity care.

There are numerous other moral issues that could be fleshed out at this point, but for which space allows only brief allusions. The likelihood of needing a major organ transplant is, I take it, a small probability event for most of my readers. This might undermine my claim that there are issues here that must be addressed by all citizens in our society. However, I would judge that all my readers confidently expect to grow old. The care of the elderly certainly represents a focal point of much moral and health policy attention. The chief reason for this is that the elderly are disproportionately recipients of health resources in our soci-

ety. Though the elderly represent only 12 percent of the current population in the United States, they are responsible for consuming about 34 percent of all health resources. The twofold emerging problem is that as the post World War II "baby boom" generation ages out, the fraction of this high health care consumption group will grow significantly. Roughly 20 percent of our total population will be elderly in the year 2030, about 62 million people. Further, this problem might be economically manageable if the relative level of health needs per person remained constant into the indefinite future. However, continuing advances in medical technology promise that the health "needs" of this generation will continue to grow dramatically as the elderly live longer and have more chronic health problems for which there will be an increasing number of costly ameliorative interventions.

Given this likely scenario, should we as a society adopt the recommendations of Daniel Callahan and others to identify an age (such as 80) beyond which the elderly would be denied expensive life-prolonging interventions?⁵ Or would such a policy be morally objectionable as a form of discrimination comparable to racism and sexism? And what about human growth hormone for the elderly? Recent research suggests that it will improve muscle mass and quality of life for the elderly but at a cost of \$13,700 per year per person? (Rudman et al. 1990; Vance 1990). Should Medicare cover those costs? Would it be fair for the public to cover those costs even though there are 37 million Americans without any health insurance at all? And if we are concerned about fair treatment of the elderly and equal moral respect for them, then what are we to conclude about the fact that the Medicare program is a uniform national program, while the benefit package and eligibility levels for Medicaid vary substantially from state to state? Relative to the poor under Medicaid, are the elderly being treated more than fairly, with something more than equal respect? The very asking of this question seems insensitive in the light of great unmet health needs of the elderly in our society, especially their needs for long-term care, home care, and a broad range of social support services. But that only serves to emphasize our larger point: there are real resource limits regarding health care. These limits become painfully evident with every advance in medical technology.

Everything said above may be taken as a very compact sketch of some major problems faced by our health care system today. The conclusions we would wish to draw from this sketch are the following. First, we cannot escape the need to make choices that will involve rationing access to health care, especially expensive life-prolonging forms of health care. The simple fact that economists properly emphasize is that resources are always scarce relative to wants and needs. Second, the problem of rationing is not merely a technical problem to be resolved by economic experts. It is at bottom a moral and political problem, the sort of problem that benefits from the knowledge and advice of experts, but that ultimately must be resolved through the processes of democratic decisionmaking. Third, to improve as much as possible the quality of those democratic decisionmaking processes, it is imperative that there be a broad public conversation of the moral issues that are involved and the policy options that are available to us. Fourth, we are not talking about a single problem that can be easily captured by a single phrase, such as the problem of health care cost containment. This problem spills over and affects a large number of health policy questions, all of which have to be addressed in a comprehensive fashion. What this suggests is the need for public policy conversations among members of the educated public that are sustained and coherent and well informed. Fifth, the most important moral notion that should serve as a focal point for such conversations is the notion of justice. What we need to formulate as a society are just health care policies that will sustain a just health care system. Sixth, we operate with conflicting conceptions of justice in our society, which are often poorly articulated in public forums. We need to improve our articulateness in thinking through our conception of justice.

Seventh, we have no reason to believe there is only one just health policy that somehow all truly rational citizens would agree upon. It is highly improbable that such would be the case. Having conceded that, we do not have to concede that it is impossible to make any moral progress in moving toward more just health policies, for we ought to achieve considerable agreement about those policies or practices in health care that are clearly unjust. If we can accomplish that much through our public conversations, we should regard that as a major achievement.⁶

Just Caring

Health Policy for the 1990s

In the remainder of this essay, I describe a project that we have proposed in Michigan, offering one model of how a socio-moral conversation regarding health care policy might be carried on that is rational and respectful of our liberal democratic political traditions. It is more complex than any of the other projects that have been part of the Health Decisions movement, but I would argue this is what the policy area itself requires.

Project Goals and Objectives

There have been two projects in the United States that have gotten a fair amount of national visibility and that provide a useful reference point for the proper design of this project. Both were *citizen-based* rather than *expert-based* projects. One was the “Oregon project,”⁷ a three-year project that covered the State of Oregon. It involved over 300 grass roots community meetings to identify what citizens in general took to be important moral and public policy issues with respect to health care. Those meetings took place in almost that number of communities. The information gathered from those meetings was fed into a citizen’s health parliament, which distilled a number of broad principles regarding the just distribution of health care resources from those meetings. The problem with this approach is its superficiality at the grass roots level. The grass roots meetings were more like gripe sessions and less like public moral conversations in which citizens would have to struggle with making difficult tradeoffs. That kind of conversation was restricted to the parliamentary representatives.

The other noteworthy project was from Minnesota. It involved a distinguished, broadly representative task force of community leaders and health care providers who sought to articulate principles for the just distribution of scarce life-saving medical technologies, especially organ transplants. This project required more in the way of public conversation by project participants, but the range of issues considered was too restricted, given the real range of tradeoffs that ought to be addressed

within the health care field. Still, both these projects provide us with important guidance. Specifically, they suggest the importance of a project's being *statewide in scope*. That helps to give a project visibility and will help to generate commitment since the project is likely to make a difference in the real world. Next, the project should cover a broad range of issues pertaining to justice and health care policy. There is something that is morally deceptive about taking a piecemeal incrementalist approach to these matters. Finally, the project ought to involve (at least as observers who have an opportunity to question and challenge) as broad a segment of the public as possible.

With the above suggestions in mind, I offer the following as project objectives:

1. To create public forums in which health care professionals and thoughtful citizens can engage in a sustained and systematic discussion of critical moral issues raised by changes in health care technology, health care delivery, health care financing, and health care policy.

2. To raise the overall level of awareness and understanding of these moral issues throughout the state through the judicious use of local newspapers and television, recognizing that only a limited number of people can participate in the face-to-face conversations envisioned under objective 1.

3. To identify and assess from a predominantly moral perspective policy options at the institutional, community, state, and national levels regarding moral issues raised by changes in health care technology, financing, and delivery mechanisms.

4. To identify as clearly and precisely as possible those "considered moral judgments" of justice that the philosopher John Rawls (1971) refers to as the shared starting points for moral conversations that address more controversial moral issues, the assumption being that this is an effective method for reaching some expanded level of agreement with respect to these controversial issues (pp. 19-20, 47-53).

5. To develop a richly nuanced and realistic moral conversation at the state and community levels, one that is both sensitive to the political, economic, and institutional constraints that make "perfect justice" impossible, and that balances what are sometimes several legitimate moral values that conflict with one another.

6. To create institutionalized state and community linkages that will assure the sustaining of this conversation after the project has been completed, in particular, linkages between an informed lay public and institutional providers of health care.

Project Design

Our best judgment is that a project of the sort we have in mind might require three years to complete, probably three years for project planners and two years for project citizen participants. In order to cover a state such as Michigan in some fashion, there should be 15 to 20 project sites, probably located in larger urban areas. (Using Michigan as an example, there might have to be 5 project sites in metropolitan Detroit, given the density of the population. Other sites could include Ann Arbor, Battle Creek, Kalamazoo, Flint, Lansing, Grand Rapids, Saginaw, Midland, Mt. Pleasant, Escanaba, Marquette, Traverse City area, Benton Harbor-St. Joseph area, Petoskey area, Grayling area. For reasons listed below, easy access to a community college, private college, or university is one criterion that should determine choice of sites.)

We envision four stages for a project. The first stage is for detailed project planning. The second stage would be the problem identification/seminar stage. The third stage would be a problem response/activity stage. The fourth stage would involve a summative project conference whose primary objective would be to articulate both a shared vision of what our health policy ought to be and a strategy for getting from here to there. Stages one and four would take place at some central location. Stage one really requires the resources of a large university or a consortium thereof. Stage four requires the visibility of the state capitol. Ideally, stage four would involve a formal engagement with the state legislature and representatives from the executive branch of government. Stages two and three would take place in the various project communities, though there would be substantial centralized coordination and resource provision from the university that served as an administrative home for the project.

Stage One: Planning and Organization

1. Identify project board and core staff

The project needs a large Board that will be broadly representative of the different interests and constituencies affected by changes in health policy. Part of the role of the Board is to give visibility and legitimacy to the project. The role of the Board is *not* to “protect interests,” but to show that fruitful moral conversation is possible among individuals with diverse interests. That means that the Board itself must be committed to rational “neutral conversation,”⁸ as opposed to partisan or ideological conversation. That also means that the capacity for and commitment to critical analysis must be an integral part of that conversation. To help achieve that ideal, it is necessary that there be 10 or so academics from diverse disciplinary backgrounds who will assist the Board (as well as project participants at various sites) in developing and using those critical skills. In addition, some core staff will be needed to coordinate and support project activities at the various project sites. This would include the development and dissemination of materials needed at the various project sites. The importance of this last task should not be underestimated. It takes a lot of creative thinking to design educational materials that will effectively stimulate and focus those community conversations.

2. Identify broad plan of project activities

It would be very surprising if the project proposed here is simply adopted by any project Board. We assume that there will be further discussion and revision regarding both the broad design of a project such as this, and the definition of project goals and objectives. Project sites would also have to be identified. It is obviously desirable that population centers be covered, though somewhat rural areas cannot be justifiably ignored since there are important health policy issues unique to that setting. A project such as this needs academic talent at the local level for the reasons cited above, so easy access to such talent ought to be a consideration. Also to be considered are local hospitals who have a Board and/or hospital ethics committee with a serious interest in the goals and objectives of this project. The Goshen project

that I directed (which was the small-scale forerunner of this larger sort of project I describe here) was successful because both the Board and the Ethics committee of Goshen General Hospital were intensely committed to the project.⁹ An entity that could facilitate access to such institutions in Michigan would be the Medical Ethics Resource Network of Michigan, which is based at Michigan State University, and which links together hospital ethics committees throughout the state. There are at least 15 such networks of hospital ethics committees in other states, which would be seen as an important resource for a project such as this, in part because they will ultimately have responsibility for articulating rationing/resource allocation policies at the institutional level.

3. Establish a project budget and raise needed funds

If I were forced to attach some sort of very crude budget figure to the project envisioned here, assuming a total life of three years, I would guess at \$35,000 per project site, plus about \$300,000 for central planning and administration costs, or about \$1 million over a three-year period for a 20-site project. This includes a lot of volunteer effort. But a project of this complexity cannot rely exclusively on volunteer effort. There is simply too much effort and responsibility required at each local site to ensure the success of the project. As for securing funding, it is not unreasonable to pursue state support for this project because it does represent a serious state responsibility; and a project such as this can facilitate legislative decisionmaking. The fact is that legislators are reluctant to undertake any major reforms of health care policy when the policy choices themselves are painful and controversial, and when no more than a small minority supports any particular reform proposal. Other sources of funding include larger foundations in the state and in communities where the project is sited.

4. Identify local project directors

A significant commitment of time at the local level would be needed to make this project work. I know that very well from personal experience. Local project directors should be knowledgeable about health care policy and some of the moral issues raised by our policy options. They should have good facilitative and organizational skills, and should

feel comfortable working with a highly diverse group of citizens and professionals. They should have some experience with community education. My own biases would incline me toward academics who are successful communicators with a broad professional public, and who are competent in fostering and sustaining the neutral conversation that is necessary for the success of this project.

5. Identify local planning committees

These local committees should probably have about a dozen or so members who are broadly representative of key health care constituencies, much like the project Board. This local committee would presumably help with recruiting and identifying individuals who ought to be part of the “core seminar groups” in each community. What we would want are individuals who have a very serious interest in the moral and health policy issues that would be the focus of this project. Working closely with each of these local planning committees would be a mini-academic consortium of three to five individuals who would have pertinent academic backgrounds and who would assist with delivering project seminars/workshops or other such educational efforts.

6. Hold a planning conference

The planning conference I refer to here would be for, say, five representatives from each project site. This might really be more of a training conference aimed at making sure that key people at each site understood the goals/objectives of the project, and had some practical direction in recruiting individuals for the “core seminar groups” at each site. Also, strategies for accessing the media should be discussed, so that the project received visibility before a large public and could produce spinoff educational effects in the larger community. Here in Michigan, consortiums of public television stations have worked with one another to develop important statewide programs. Similar arrangements are possible in other states. This project seems ideal for that kind of cooperative effort. Also, in these training sessions there would have to be discussion of mechanisms for stimulating and focusing the conversations that would occur in each of the core seminar groups.

Perhaps the first third of that planning conference ought to be given over to laying out the broad range of problems I alluded to in the first part of this essay for purposes of establishing some shared sense of vision and purpose among participants. The last two-thirds of the program would be given over to exploring various ways in which the project might be implemented at the local level, with special attention given to identifying and resolving potential implementation problems. I envision this as a long one-day conference. That may not be a realistic time frame.

It might also be very desirable to spend a week in the summer training those academics who will have the most direct involvement with the project seminars at each site. Much of that week might be spent modeling, practicing, and testing different ways in which those community seminars might be run. It is critical that there be genuine conversation among seminar participants (as opposed to a series of questions directed to faculty facilitators), and that these conversations be focused and directed.

7. Develop educational resources needed locally

The second stage of the project, what I shall refer to as the community seminar stage, is modeled on the Goshen project that I directed. The central premise of that project was that successful community discussion of issues of justice and health care policy required community conversations that had depth, that were comprehensive, that were well organized, and that were sustained over a period of time. In order to achieve that objective, considerable resources had to be developed in that project, such as newspaper essays, very detailed leader's guides for community seminars, reading materials for each seminar, guides for the work of project task forces, and so on. This required a lot of time and energy, but it certainly resulted in community discussions that were much more focused and productive. If that same effort were required of each project director at the local level, I doubt very many would be interested in attempting the project. Or else project costs would escalate enormously. Consequently, my recommendation is that the educational/publicity resources needed for the project be developed in a centralized way. I can guarantee that this will not produce carbon copy

conversations at each site, but will instead facilitate greatly the ease with which such conversations can be initiated.

My suggestion is that for each seminar/workshop there ought to be four to six articles that are required reading for each member of the core seminar group, about 40-50 pages. The sort of articles I have in mind are those that discuss issues of ethics and health policy in professional health care journals, or in publications such as *The Hastings Center Report*. Such articles are generally not excessively academic and opaque.¹⁰ Those articles should be as balanced as possible in terms of reflecting alternative points of view on these policy issues, since there are many reasonable but conflicting points of view on these matters. In the past I also developed leader's guides (four to six typed pages) to accompany each packet of articles. The guides focus attention on specific issues, assist the reader in reading more carefully and critically, and articulate a number of issues that can serve as focal points for discussion in the seminars themselves. The guides also provide cases and exercises for stimulating conversation in the group.

For the project we envision in Michigan, we plan to produce a book-length manuscript organized into 20 chapters that will be coordinated with each of the community seminars that are planned. Each chapter will be a combination of an essay introducing the specific issues that will be the focus of that seminar, and a leader's guide geared to the readings that project participants will be doing for that session. Like the earlier leader's guides, this will also provide specific questions that will give focus and direction to each seminar. The larger objective I have in mind is developing a resource that will have utility as a stimulus for such community conversations elsewhere in the United States.

I also wrote a number of newspaper essays that were published in the Goshen paper just prior to each seminar. These served as a way of involving a larger public in the project. Such essays could also be produced locally for the opinion pages of local papers, depending upon the time and commitment of local academics/participants. This is something that we strongly encourage, because this is a way of drawing these issues to the attention of a public larger than those who can participate in the seminars themselves.

Stage Two: Project Seminars and Workshops

1. *Identify local core seminar groups*

I think there ought to be a “core seminar group” in each community. This could be anywhere from 25 to 50 people who would be invited to be part of the group. About half these people should be connected with health care as providers or administrators or insurers. The other half ought to be broadly representative of the community at large and should themselves be part of the “educated lay public,” who understand the importance of reading and are willing to make a commitment to do a fair amount of it. When I say “broadly representative” I mean those groups who are affected in significant ways by health policies. That means both large and small businesses, organized labor, the elderly, the poor, disability groups, and so on.

We would want in this core group people who already have some sort of knowledge base regarding health care policy and the concerns of this project. Members of this core group would commit themselves to attending all of the seminars that would be part of this stage of the project, and they would also commit themselves to participating in whatever activities were part of stage three. They would also commit to doing the reading, since this is the key to having an informed community discussion as opposed to just exchanging prejudices. In the course of organizing this project in Michigan, I have discovered that there is a surprisingly large number of citizens in our society who are significantly involved in health policy groups of one kind or another. These are the sorts of individuals who already have a strong knowledge base in the area, who have the requisite energy and interest, and who would seem to be the group from which seminar participants are most readily recruited. Further, these are the sorts of individuals who will just naturally carry on the project conversation in the larger community long after the formal project has concluded.

Each seminar would last two hours. The first half-hour can be given to a panel presentation or key speaker, just to get things rolling; the rest can be for organized discussion emerging from the readings, the leader guide, or suggested exercises. The public at large should be invited to attend all these sessions, but they are there primarily as observers

because, presumably, they will not have invested the time and energy in reading and reflection that members of the seminar group proper will have done. This is not intended to be antidemocratic. Rather, the practical objective is to create a sense of identity and cohesiveness among members of the seminar group proper. My experience shows that this is necessary in order to facilitate the conversational process in the group itself. That is, group members begin to develop a sense of where other seminar members are coming from, which is important for achieving a certain level of psychological comfort necessary for candor. It needs to be kept in mind that the issues to be addressed are both intellectually difficult and emotionally charged.

2. *Seminar topics*

The same topics should be chosen for all the community seminars. Common topics are essential to preserve the statewide nature of this moral and public policy conversation. My recommendation would be that there should be two series of seminars, perhaps 10 weeks for the first set and 8 weeks for the second, with either a winter or summer break, depending upon how they are scheduled. The first series of seminars would serve as an introduction to the major areas of current health policy attention, including the relevant issues of justice, with one seminar focusing on each area. The second series would focus on universal health insurance proposals, or, more generally, proposals aimed at restructuring the way in which we finance health care in America. This latter focus seems to be dictated by emerging policy debates, reflected both in congressional deliberations and in discussions in professional health journals. Though that is a national issue, the issue at the state level that has precipitated that debate is the issue of what ought to be done about the growing number of uninsured in our society, a highly heterogeneous mix whose needs are not readily met by current health financing options.

I am not quite sure how this second series ought to be organized. There are at least eight major credible universal health insurance proposals on the agenda now. Maybe each one of them ought to be a focus of a seminar, the object of which would be to assess each one from the perspective of about a dozen assessment (value) criteria that would

have been introduced in the first series of seminars. Of course, one of the options would be that we do nothing at the national level, that each state be left more or less on its own to work out its own policy solutions.

What I imagine as the lead-off seminar at each site would be what I call a “big picture” seminar aimed at giving everyone a sense of the range of health policy issues that must be addressed in public forums and how these issues are connected with one another. That seminar would then be followed by seminars of the sort listed below. Space does not permit a complete listing.

- *Health Care, Justice, and the Elderly.* How might we justifiably set limits on the demands that the elderly make on the health care system, bearing in mind that all of us aspire to be among the elderly some day?
- *Health Care, Justice, and the Poor.* To what extent as a society are we morally obligated to provide for the health care needs of the poor, the uninsured, and the underinsured?
- *Health Care, Justice, and the Terminally Ill, Chronically Ill, and Critically Ill.* How can we justifiably limit the demands that these very needy individuals make on our health care system? Justice may not require doing everything possible, though compassion pushes us in that direction. Still, we are rationally disturbed that we might spend so much and achieve so little in the way of benefit for these individuals. AIDS, of course, fits in under this topic.
- *Justice, Health Care Cost Containment, and the Development and Dissemination of Expensive Life-Prolonging Technologies.* This includes technologies such as organ transplants and artificial hearts.
- *Justice and the Financing of Health Care in America.* Would we have a fairer system for financing health care if we adopted some version of national health insurance, perhaps something along the lines of Canada?
- *Justice and Health Care Cost Containment Approaches.* Assuming that we really must do something to control escalating health care costs, what mix of policies and approaches would be most fair, all things considered?

- *Justice, Health Care, and the Good Physician.* The fact is that 70 percent of all health care dollars are allocated as a result of physician decisions. That effectively makes the physician the gatekeeper to the health care system; and it would imply that he/she ought to be primary rationer of health care sources at the level of the patient. That, however, conflicts with our traditional expectation that physicians will be absolutely loyal to the welfare of their patients.

Stage Three: Critical Value Inquiry

The primary objective of stage three is to acquaint project participants with the broad range of issues we must face more or less simultaneously with respect to making health care policy choices. This will require the making of more systematic, and presumably more thoughtful and more fair, tradeoffs among competing moral and social values. In my mind, the primary objective of stage three is to actually make an effort to work out some set of tradeoffs, and to make explicit the principles and value commitments that govern the choices made. There are really two tasks that need to be undertaken here. The first of these should be the "value inquiry/value tradeoff" task described below. The second should be a working paper in which participants apply the results of their value inquiry to the task of articulating both a state-based and a national policy regarding access to health care. Presumably, this second task should be the natural outcome of the second set of seminars that had focused on the issue of universal access/universal health insurance.

1. Value inquiry/value tradeoff exercise

The value exercise I would recommend is based upon something called the "Delphi technique." We start by imagining that as a society we want to commit no more than 12 percent of GNP to health care, which was a little over \$660 billion in 1990. Then everyone is individually given a survey form with 70-90 budget items for health care that might be described in some detail. We might ask, for example, whether we should continue to spend \$1.5 billion per year to sustain the 10,000

people who are in a persistent vegetative state, just like Nancy Cruzan. Or do we wish to make available 40,000 totally implantable artificial hearts for those under the age of 65 at a cost of \$6 billion per year? Or would we be willing to spend \$15 billion to make up to 100,000 implants per year available to all who have the relevant medical need regardless of age? Individuals would make their choices among the possibilities up to the specified budget limit. There could easily be \$1 trillion worth of choices, which means a large portion of our health wants/ needs would not be funded. To simplify tabulating, we could use a computer score sheet. We would also ask these individuals (the seminar participants) to list the moral principles or other social values they used in making each of their choices. Again, it might be possible to provide a list of 30-50 such "value justification statements" that someone might choose from. Individuals would be asked to make a copy of their choices for their own records.

All of these surveys would be tabulated at some central site. Participants would then get two sets of aggregated results. One set would be their local aggregated results, the other would be the statewide results. Seminar participants would then get together to discuss these results among themselves, perhaps for three sessions of two hours each. They could "make a case" for affirming or rejecting whatever the aggregated results were on each item. After this discussion takes place, the same survey is once again filled out by all, and the results are once again aggregated to see what sorts of changes take place as a result of the group interaction and assessment. If people are willing to commit the time, then this second round of aggregated results should be discussed and assessed by the group, after which the survey is completed a third time.

Throughout this exercise it is important to keep in mind two things. First, the objective is not to achieve some sort of agreement on a societal health budget as such. Rather, the objective is to use this budgetary exercise as an effective way to explore the moral and social values individuals believe ought to serve as a basis for making fair and efficient allocations of health care resources. Second, there is nothing morally commendable about one group in society making rationing decisions that will affect the lives and welfare of another group. Hence, it is very

important that this exercise be structured in such a way that it is clearly recognized that we are making rationing choices for ourselves and our loved ones. There is a real world circumstance that we ought to be facing up to now, namely, that the post World War II “baby boom” generation is aging out and will make enormous demands on the health care system starting in the years 2010 through 2035. If we, the members of that generation, are unwilling to bear those expenses ourselves, then now we ought to begin making the rationing decisions to which we will bind ourselves in the future.

2. Critical final paper

As noted above, each core seminar group should apply the results of the prior inquiry to the task of articulating a policy proposal related to the issue of universal access to health care. Such a paper would reflect the discussions of the group from the second set of seminars, as well as the results of the value inquiry exercise. This is the product that would be brought to the summative conference that would conclude the project.

Stage Four: Summative Conference

This last stage of the project is something that is far from clear in my own mind. It has to be the integrative stage of the project. We might follow the lead of Oregon and Minnesota in this matter and see this summative conference as really a “Health Congress.” Each project site would then send some limited number of delegates to this congress. Their task would be to make some specific health policy recommendations that would reflect both the results of the third “Delphi” survey and the papers that had been prepared at each project site. I was recently a participant in a conference that employed a “futures methodology” for defining and integrating the views of the professionals and disciplinary experts who were part of that conference. It struck me that that approach would apply nicely to what we were trying to accomplish here, since this approach involved an explicit integration of values, policy choices and strategies for effecting those policy options. Another possibility is that this “congress” would not just meet on its own. Instead, this would be a sort of joint meeting with the state legislature. Again, a key

objective of such a conference would be to engage legislators in the debate rather than to allow them to just listen passively.

From this conference, some sort of public document ought to emerge, though this document would not be a “final report.” Rather, it would serve as a starting point for future public moral conversations about the nature of just health care policies and practices. Ultimately, I think it would be desirable if we, as a society, could hammer out something like a “just health care constitution,” a practical document that sought to spell out in an explicit and principled way the sort of balances that had to be struck among the many competing values and constraints and considerations that must shape our health care system and health care policy. That requires an even longer and more sustained public conversation, but I believe the sort of project proposed here would make a good start in that direction.

To conclude, a project of this magnitude, properly organized and managed, is likely to have a significant impact in shaping health policy at least at the state level, especially if well managed. It should certainly garner significant media attention. And it should serve as a model for intelligent public policy debate in other states and for other policy areas. One of the things that is assumed is that members of those core seminar groups should be chosen because they have the capacity to educate and influence their constituents or professional peers. What they need to do that effectively are the sorts of resources that would be developed through this project.

NOTES

1. The most vocal defenders of invisible rationing are Guido Calabresi and Philip Bobbitt in their book *Tragic Choices*. The title of their book nicely captures the core of their basic argument, namely, that in matters of health care rationing at the level of social policy, we will always be confronted with tragic choices, choices which will necessarily require that we violate some deep social value. This is because the value conflict is such that to choose one is necessarily to violate the other. Hence, their practical recommendation is that to avoid “exposed choices against life” and “exposed inegalitarianism” (and the social rancor that might be precipitated), these choices ought to be made through social choice mechanisms, such as markets, that will effectively hide the fact that such choices are being made.

2. I have argued against the moral legitimacy of invisible rationing mechanisms in health care in two of my articles (Fleck 1987, 1990a).

3. For a more detailed discussion of this issue, see my article "Pricing Human Life: The Moral Costs of Medical Progress" (1990b). What has emerged more recently is the case of Helga Wanglie in Minneapolis. She is an 87-year-old woman who suffered a very severe heart attack in May of 1990 that resulted in her being reduced to a persistent vegetative state dependent upon a respirator and ICU care. Her husband and two children insist that she herself would have wanted to be sustained in this state indefinitely using all available medical technology. In late 1990, her physicians went to court to ask permission to remove her from the respirator (thereby causing her death) because her care was futile, and there was no medical obligation to provide such care. More noteworthy, however, is that by June of 1991 her care had cost in excess of \$1 million. The real issue we need to address here as a society is whether anyone in such circumstances has a just claim on resources of this magnitude. See Miles (1990).
4. For an excellent discussion of these moral issues, see Daniels (1990).
5. See Callahan, *Setting Limits. Medical Goals in an Aging Society* (1987) and Daniels, *Am I My Parents' Keeper? An Essay on Justice Between the Young and the Old* (1988). These two books have sparked an intense debate on the issue of age-rationing. One critical response is Kilner, *Who Lives? Who Dies? Ethical Criteria in Patient Selection* (1990).
6. As noted in the text, I could only present a sketch of the problem of justice as that pertains to health care policy in the United States, and I could only sketch a justification for the moral claims I advanced. The interested reader may find a more detailed analysis in a paper I prepared for the Governor's Task Force on Access to Health Care [Michigan], which has been published as part of the final report of that task force. [See Volume 3, *Background Research Papers*, 109-18.] The paper is titled "Health Care and the Uninsured: Choosing a Just Social Policy." The arguments for the claim that health care policy is a matter of social justice rather than social beneficence may be found in my papers "Just Health Care (I): Is Beneficence Enough?" (1989a) and "Just Health Care (II): Is Equality Too Much?" (1989b).
7. See Crawshaw and others, "Oregon Health Decisions: An Experiment with Informed Community Consent" (1985). A more detailed description is available in a project booklet by Brian Hines, *Oregon and American Health Decisions* (Salem, OR: 1985). More recently, Oregon has garnered considerable media attention for its effort at priority setting and rationing in the state Medicaid program. One of their more controversial tradeoffs would deny organ transplants to Medicaid recipients in exchange for expanding the program to cover 100 percent of the poor in the state as opposed to the current 58 percent. See the article by the physician who is president of the Oregon Senate, John Kitzhaber (1990).
8. This phrase is borrowed from the political philosopher Bruce Ackerman, for whom this is a central practical and philosophic notion in his book, *Social Justice in the Liberal State* (1980).
9. The Goshen project is very well described in a 30-page project booklet available from Goshen General Hospital in Goshen, Indiana. That booklet is titled, *Just Caring: Justice, Health Care and the Good Society*. The project itself was carried out in 1985-87.
10. An excellent example of the sort of essays I have in mind for project seminars are the pieces that David Eddy has been doing in *JAMA* on an occasional basis. They are clear, brief, problem-focused essays that also suggest alternative ways of thinking about issues of health care rationing. These essays nicely integrate the moral, political, economic, and organizational dimensions of these issues. They all appear under the column heading "Clinical Decision Making: From Theory to Practice." The first essay appeared in volume 263 (January 12, 1990). The most recent essay appeared in volume 265 (May 8, 1991). There have been 13 essays so far.

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