

## SYLLABUS PHL 870

### SEMINAR: JUSTICE AND HEALTH CARE POLICY (FALL, 2008)

#### FACULTY:

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**COURSE TEXTS:** Setting Limits Fairly: Learning to Share Resources for Health (2<sup>nd</sup>) by Norman Daniels and Paul Sabin (Oxford University Press, 2008); Medicine and Social Justice: Essays on the Distribution of Health Care, edited by Rosamond Rhodes, Margaret Battin, and Anita Silvers (Oxford University Press, 2002); Just Health by Norman Daniels (Cambridge University Press, 2008). From Chance to Choice: Genetics and Justice by Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler, (Cambridge University Press, 2000). In addition, a large reading packet has been prepared with articles from assorted professional and philosophic journals. Specific readings are listed with each class on the syllabus. Details regarding availability of the reading packet will be provided in class. Actually, much of the required portion of the reading packet will be loaded on the ANGEL website for the course. My own book should be in print sometime in the Fall from Oxford University Press. The title of that volume is Just Caring: The Ethical Challenges of Health Care Rationing and Democratic Deliberation. I will load several chapters from that volume on the Angel Web site. **I know I am asking you to do a lot of reading, which became more evident as I finished constructing this syllabus. I don't want anyone to have a nervous breakdown (or broken back) from the reading. So do as much as you can, mindful of the need to do an equal amount of *reflecting* on what you read so that you can participate fully in the seminar. This latter objective is what is MOST IMPORTANT.**

**ASSIGNMENTS:** Graduate students will be expected to do several (five or so) short (1-2 page) critical assessment papers during the course itself related to one or another of the readings for that evening. This is intended to prepare you more adequately for seminar discussion and to get some feedback from me before your final paper is due. You will be expected to do one 20-30 page final paper. You should have a well-focused problem for this paper by the mid-point in the course, which you should discuss with me (for approval and practical advice).

If there are any advanced undergraduate students in the course, you will be expected to do three short critical papers and one 10-15 page final paper. Topics for the final papers should be approved and discussed with me somewhere around the mid-point of the course.

GRADING: Short papers and seminar participation will count for 40% (30/10) of your final grade; the final paper will count for 60% of your final grade.

**PRIME DIRECTIVE: Read, Read, Read.**

Other graduate seminars in philosophy require considerable reading, often very dense philosophic reading. The reading required in this course will generally not be that dense, but it is necessary to do a lot of non-philosophic reading about health care politics, health policy, health economics, health care organization, the role of professions in health care, emerging health technologies etc. in order to appreciate accurately and adequately the shape of the moral problems we address. I will provide a lot of direction in this regard; having philosophic interests in an area such as this requires a lot of empirical knowledge. **PAUSE:** Just to alleviate the anxiety the earlier part of this paragraph might have induced, in the course itself I will introduce you to a considerable range of relevant empirical information related to health care. You will do some modest reading of similar material. But I do not expect you to acquire the range of empirical knowledge I have acquired over thirty years in one semester. Rather, my goal is to sensitize you to the sort of reading you must be prepared to do to address philosophic problems in health care intelligently.

**DOUBLE PRIME DIRECTIVE: Don't lose focus; don't lose hope!**

As I construct this syllabus (I was half way through and I returned to this point) it became clear to me that in no single seminar meeting are we likely to reach some neat closure on the issues we discuss that evening. There will be numerous loose threads, complex interwoven themes, unresolved critical comments, partial and inadequate arguments, infelicitous vagueness, and much else that will make philosophic minds discomfited. That is the very nature of these kinds of problems, especially when they are connected to complex rapidly changing features of the world of health care.

I have in mind two ways (right now) for maintaining continuity across seminar sessions. First, our task will be to refine "in application" various strands of our conception of health care justice-----a libertarian strand, a utilitarian strand, a moderate egalitarian strand, a strong egalitarian strand, a fair equality of opportunity strand, and a democratic deliberative strand. Second, we might have more than forty paradigmatic cases that I will introduce the first seminar meeting to which we will constantly return. Some of these cases are well known in the health

care justice literature----Baby K (anencephalic infant), Lakeberg conjoined twins, Helga Wanglie (87 yr old in persistent vegetative state), Coby Howard (8 yr old with advanced leukemic cancer in Oregon. Others have appeared in relatively recent news accounts because of all the public attention that is being given to escalating health care costs and/or desirable/evil rationing decisions. Having a complex range of cases will help us in the task of articulating more refined considered judgments of health care justice at various levels of specificity. The general idea is that we will be seeking a capacious enough conception of health care justice that we will be able to construct reasonable responses to the allocation challenges posed by each case.

### **COURSE OBJECTIVES:**

- ◇Critically examine approaches to non-ideal moral reasoning  
[Consider the role of philosophers in shaping public policy, as in the case of President's Commission from early 1980s or Clinton Administration (1993-94) or Bush Bioethics Council chaired by Leon Kass.]
  
- ◇Become familiar with a broad range of issues of justice connected with health care policy, including what will count as a just approach to health care financing, or a just approach to health care rationing, or just access to the health care system, or just health care planning with respect to the dissemination of expensive life-prolonging medical technologies, and so on
  
- ◇Critically assess competing theories of health care justice, which would include libertarian (Engelhardt), utilitarian (Eddy), strongly egalitarian (Veatch) and moderately egalitarian (Daniels) conceptions of health care justice
  
- ◇Achieve a comprehensive understanding of the many dimensions of our health care system that have a legitimate bearing on moral judgments we would make about that system, i.e., the role of physicians, types of managed care plans, how health care is financed, how public policy affects health care, role of profit motive in health care today, etc.
  
- ◇Explore the usefulness of Rawls' method of reflective equilibrium in addressing/ assessing policy options from a moral point of view, as well as the utility of Rawls' notion of public reason in addressing these issues.
  
- ◇Explore conceptual problems of making moral judgments in complex, dynamic social systems.
  
- ◇Critically assess some popular moral ideals connected with health care and health care policy, such as the notion of the "pricelessness of human life"

or a general "right to health care".

- ◊ Critically assess the moral appropriateness of rational democratic deliberative processes in connection with making trade-offs and establishing health care priorities for purposes of health care rationing/ cost containment. actually, what we will need to assess are different conceptions of what reasonable and legitimate processes of rational democratic deliberation ought to look like.
- ◊ Articulate as precisely as we can "considered judgments of health care justice" with respect to each of the problem areas we address

## INTRODUCTION

For most of the past thirty years my academic research has been focused on what I refer to as the "Just Caring" problem. That problem is best summarized in these three questions: (1) What does it mean to be a "just" and "caring" society when we have only limited resources to meet virtually unlimited health care needs? This is the "just caring" problem at the macro-level, the level of federal and state health care policy. (2) What does it mean to be a "just" and "caring" hospital or health insurance plan or managed care plan when you have only limited resources to meet the disproportionate health needs of those for whose health you have some degree of responsibility? This is the "just caring" problem at the meso-level. (3) What does it mean to be a "just" and "caring" physician (or nurse, or social worker) when you have only limited resources to meet the disproportionate health needs of your patient before you? This is the "just caring" problem at the micro-level, the level of individual caregivers and individual patients.

Implicit in the "just caring" problem as I understand it are the following claims:

(1) How health care is distributed in our society is fundamentally a moral/ political problem, and only secondarily an economic, managerial, or organizational problem (though these secondary considerations clearly have moral relevance and must be taken into account in forming our considered moral judgments in these matters);

(2) The need for health care rationing (denying individuals what from a societal/ organizational perspective are non-costworthy, marginally beneficial health services) is inescapable;

(3) The fundamental moral value at stake with respect to the problem of health care rationing is that of justice, the implication being that there is no generic, all-encompassing right to health care, but only context-specific rights to health care that will be derived (in part) from a certain conception of health care justice;

(4) What is most morally problematic about health care rationing (as things are now) is that:

(a) it is done invisibly, in ways that are hidden from either individual resistance or public scrutiny (which violates the "publicity condition" that is a core value in our shared conception of justice), and

(b) rationing typically involves the healthy, wealthy and politically powerful imposing rationing decisions on the sick, the poor, the vulnerable, the politically powerless (which prima facie violates respect for personal autonomy and

the other moral principles that are at the heart of a contractarian conception of social justice);

(5) The key to correcting the moral problems identified in (4) is to devise social policies and social practices that implement health care rationing in ways that are essentially public and self-imposed, which is through a process of rational democratic deliberation that is both liberal and constrained by a set of contractarian social justice principles [what is rejected here is the view that markets should be the principle mechanism through which we achieve just health care rationing, which implies there are some health care distributional contexts in which markets would be a morally defensible mechanism];

(6) The judgments of health care justice that emerge from this process of rational democratic deliberation will be non-ideal, but nevertheless they will be morally justified to the extent that they represent a moral improvement (more just state of affairs) over the status quo ante, and to the extent that they are a product of free agreement/ fair bargaining among the rational social contractors who may be affected by these judgments in practice;

(7) In a resource-constrained environment, such as a managed care plan, the key to extracting physicians, who must make rationing decisions, from what appears to be an unsolvable moral dilemma [the obligation to be both just and prudent gatekeepers of social resources, and loyal advocates of the best interests of each of their patients] is that there should be rationing protocols/ processes that their patients have collectively and freely agreed to through this process of rational democratic deliberation.

The seven propositions above capture most succinctly the core argument of the book that I have written. This is an ambitious book. Its aim, with respect to the problem of health care justice, is to achieve both a level of theoretical rigor comparable to John Rawls' A Theory of Justice and a level of practical applicability (for clinical and policy purposes) comparable to Beauchamp/ Childress' Principles of Biomedical Ethics. [Note: Beauchamp and Childress today will concede that their book is not titled as aptly as they might like in that the title suggests a rational deductive approach to problem solving in medical ethics. In fact, their methodology [certainly in the fourth and fifth editions] is much closer to that of reflective equilibrium, which both Rawls and I endorse, and which is much more sensitive to the empirical features of problems in health care ethics.] In order to achieve this dual objective our inquiry will proceed along practical and theoretical paths more or less simultaneously. That is, our methodology will be very Deweyan.

Our methodology is Deweyan in that it will be constructed in response to the practical moral problems of health care justice at the clinical/ institutional and policy levels that require a theoretical perspective for their resolution. And, as in Dewey's work, there

will be a heavy reliance on a certain conception of democracy and democratic deliberation as providing important tools for addressing the problems of health care justice in the real world, in the context of dynamic political and economic systems shaped by a certain political and economic history. Thus, in the early chapters of this volume (and in our first couple seminar sessions) we will be articulating a representative range of these problems. Examples would include: Is it just for a hospital to deny very expensive life-prolonging medical interventions (heart transplants or autologous bone marrow transplants or these very expensive cancer drugs or artificial hearts) to individuals who have no ability to pay, i.e., individuals who would make very large claims on the charity budgets of hospitals? Is there anything unjust about the fact that hospitals create charity care budgets by overcharging their paying patients? Alternatively, are very large managed care plans that extract large discounts from hospitals on behalf of their members unjust because they substantially diminish the capacity of these hospitals to provide charity care? More broadly, who ultimately should be morally responsible for meeting the health care needs of the 47 million Americans currently without health insurance? Should this be the responsibility of local hospitals and physicians? Local government? State government? The federal government? Employers (since the majority of the uninsured are employed at low-wage jobs without health benefits)? Should just and caring hospitals have an explicit prioritization process for the use of charity care dollars (as opposed to haphazard, unstated, potentially arbitrary access rules)?

How should just and caring managed care plans establish rationing protocols/ health service priorities within their plan? How can we reasonably judge whether specific cost-constraining incentives in a managed care plan that are aimed at shaping the behavior of either physicians or consumers are just or not?

Is it unjust to deny individuals who are above a certain advanced age access to absolutely scarce life-saving medical resources, such as transplantable hearts or ICU beds? Given the disproportionate demands on the health care system (health care needs) of the current generation of the elderly (who make up 13% of the population but consume 35% of health resources in any given year [\$830 billion in 2007]), and given the graying out of the "baby boom" generation, which will make up 21% of the population in 2025, what sorts of policies for health care rationing for this future generation would be just and caring?

Is there anything unjust about permitting the likely healthy in our society segregating themselves into insurance pools that exclude those with the greatest actual or possible health care needs so that the more healthy can purchase excellent health services at very affordable prices? This is the issue raised by currently fashionable Medical Savings Accounts. [From a libertarian perspective it certainly seems reasonable that individuals should be allowed to sort themselves in this way, perhaps under some interpretation of a right of free association. But from an egalitarian perspective the actual results are very morally problematic because those who are likely to have the greatest health needs and the greatest health costs will be least likely to afford the health care that they need.]

**Is there anything unjust about the fact that federal policy permits the middle class to have health insurance through their employers that is tax-free (which is equal to a 40-45% subsidy of the cost of that insurance) while denying any such assistance to the uninsured working poor in our society? That tax subsidy has a current value to insured Americans of about \$200 billion.**

**The problems listed above are a very brief sampling of the issues that require a coherent, comprehensive, theoretical account of health care justice for their resolution. The task of the central chapters of my book has been to provide that account (and working out the details of that account will be the central philosophic challenge of this seminar). What is distinctive of the account of health care justice that I will offer is that it is pluralistic [there is no one principle or lexical ordering of a small number of principles that will yield an adequate theory of health care justice], non-foundational/ experimental [no rationally intuited principles of justice that are immune to criticism and revision in the light of future experience], coherentistic/ constructivistic [justification of our account of health care justice is a product of a certain reflective equilibrium among the various elements of the theory, our considered moral judgments about specific cases and policy proposals (which may be expressed through professional dialogue and/ or rational democratic deliberation), and more or less plastic features of the health care policy environment that would include organizational/ institutional constraints and possibilities, economic and political and psychological constraints and possibilities, technological developments, legal and religious constraints, and professional norms], and rationaly democratic [because theoretical reason is limited in its capacity to solve social/moral problems "all the way down," that is, we will often get down to a level of concrete detail with respect to many problems of justice where we have nothing in the way of theoretical resources that will yield a uniquely morally preferable/ uniquely rationally correct solution, at which point we turn to processes of rational democratic conversation to yield a concrete choice that is "just enough" or "fair enough," all things considered]. Virtually all just rationing decisions, at whatever social level, should ultimately be made within this rational democratic social space. We do wish to emphasize that this is rational democratic deliberation and decisionmaking, as opposed to the irrational (power-dominated, ignorance-driven, appearance-preserving) democratic practices that shape much of our social discourse now. Still, the reasonable question can be raised as to what it is that makes these democratic conversations rational and the products of these conversations morally legitimate. The short answer to this question is that these conversations are rational and morally legitimate to the extent that they are a product of "public reason" as that notion is understood by Rawls [1993, 1995] and Habermas [1995].**

**Public reason can be thought of in two modes. In its theoretical [Rawlsian] mode public reason is responsible for the construction, interpretation, specification, and mutual adjustment of what I refer to as "the constitutional principles of health care justice."**

There are at least ten such principles which comprise the broad framework of our pluralistic account of health care justice. There is no intrinsic hierarchy among these principles, nor is there any algorithm for determining the relevance or weight of these principles with respect to some particular problem of health care justice. [In the abstract this will appear to create enormous theoretical gaps for the exercise of wholly arbitrary judgment, but in practice we will see that this is not true (or perhaps we should say that it is not excessively true). I suspect that if we could take the time to explore the field of constitutional law we would discover that there are in fact numerous “principles of constitutional law.” I have never read anywhere of someone identifying a grand principle of constitutional law, nor have I read any defense of some unique lexical ordering of constitutional principles. In spite of such lack of ordering we seem to be able to use our constitution to address well enough a large number of difficult legal and political problems, and we have been reasonably successful in doing this for a period of more than 200 years.] I refer to these principles, using a legal/ political analogy, as constitutional principles of health care justice because they circumscribe the "space" of just rational democratic deliberation. That is, democratically determined rationing policies and practices that violate these boundaries are by that very fact unjust. We might be tempted, for example, to have as a rationing protocol denying expensive life-prolonging medical care to AIDS patients when we can confidently predict that they have less than a 10% chance of surviving another year. Such a proposal, however, would be presumptively unjust unless some morally compelling account could be given as to why AIDS patients should be marked out in this way. [At the very least an "equal consideration and respect" principle would seem to be the violated boundary principle.] By way of contrast, we could rationally and democratically approve a rationing protocol that would deny expensive, life-prolonging medical care to all terminally ill individuals for whom we could confidently predict they had less than a 10% chance of surviving another year. This is because any one of us could find ourselves in precisely these circumstances at some point in the future; and hence, such a choice for prioritizing access to health care seems suitably impartial. [An important moral assumption, discussed below, with respect to this last example is that the "we" who articulate and approve this rationing protocol are the "we" who will have to live with this protocol.]

Public reason also has a practical [Habermasian] mode. In that mode public reason in rational democratic deliberation is responsible for the construction and mutual adjustment of social policies and practices for fairly and rationally and democratically resolving the indeterminacies, priorities, and trade-offs associated with health care rationing at the level of concrete social practice [in a clinical setting, in a managed care plan, in the legislative arena].

The last ten chapters of my book (and probably nine or ten seminar sessions) will be devoted to addressing a range of justice-relevant clinical and policy issues. Examples of such issues would include: What are the just claims to expensive, marginally beneficial, limited health care resources of the terminally ill [confident judgment of less than a year of

life, even with aggressive treatment]? The elderly [over age 65]? The hyper-elderly [over age 85]? The catastrophically ill? The chronically ill? The seriously mentally ill? The mentally troubled? Individuals in a persistent vegetative state? Individuals with end-stage dementia? Individuals seriously physically disabled? Infants born under 700 grams, 23 weeks gestation? Infants with necrotic bowel syndrome? Anencephalic infants? Infants with other gross brain anomalies? Infants doomed to a very early death [less than 7 years] as a result of a serious genetic defect? Individuals whose serious health problems are largely a result of their own less-than-responsible choices? Individuals who are repeatedly hospitalized with the same disease because they fail to exercise adequate control [diabetics out of control, drug abusers, alcoholics, individuals in congestive heart failure who smoke or fail to attend to their diets, etc.]?

How can we determine what counts as a just allocation of health care resources to medical research? Are desperate individuals (facing near-certain death within a year because of their medical problems) treated unjustly if they are denied access to publicly-funded research trials (which represent their only chance of being saved) because the totality of their medical problems are such that they would not yield "clean data" if they were chosen as research subjects?

What criteria should be used for determining who has the most just claim to the "last bed in the ICU"? Should medical effectiveness be the dominant criterion, which would mean that individuals who have the most to gain in length of life and quality of life would have the strongest moral claims? Would the application of such a criterion result in the unfair treatment of those who were afflicted with some serious disability (perhaps from birth, perhaps as a result of an accident)? Would it be unjust to remove individuals from the ICU when new patients needed the ICU and were more likely to derive more benefit from access to the ICU than some current patient?

Are there some types of health care services that are justly distributed on the basis of ability to pay? In other words, it would not be unjust to deny individuals access to those services because they could not afford them. What criteria can we use to determine what those services are? Should, for example, transplantable organs ever be distributed on the basis of ability to pay? That is, is it unjust that the well insured would have preferred access to such scarce expensive life-prolonging medical technologies? In this connection it is worth noting that we have seen the development of a Totally Implantable Artificial Heart [TIAH] in 2003 (now in expanded clinical testing). [What we have already in place that is proving to be an equally challenging moral problem is the left ventricular assist device, intended to provide an extra year or two of life for individuals in congestive heart failure at a cost of \$180-200,000 per person.] There is a potential annual need for the artificial heart in the vicinity of 350,000 at a cost of \$300,000 [\$2007] each, the average gain in life expectancy being about five years. More than 70% of these would go to individuals over age 65. Would it be unjust not to have this as a Medicare covered benefit, the result being that the wealthy elderly could afford it, but not those who were less well off? Would it be

unjust to deny TIAHs to Medicaid beneficiaries or the uninsured in our society (both being non-elderly individuals)? Would it be unjust to allow individual employers to determine whether or not it would be a covered benefit in their health plans? Would it be unjust if only senior managers in a corporation had this as a covered benefit?

The genetic endowment that each of us has at conception, with whatever future disorders/ deficiencies might be built in, is usually taken as a moral given, a moral baseline, something that may be a matter of good fortune or misfortune, but not a matter of justice or injustice. However, future genetic research and technological breakthroughs, especially in the form of embryonic genetic therapy, will call that assumption into question. The potential is there for altering radically what would count as fair equality of opportunity in our society. Further, it is fair to assume that such genetic embryonic therapy might be very expensive, say, \$50,000 per embryo. Given these altered assumptions, what would be the just claims of all future parents in our society to such benefits for their future children? Would it be just if such interventions were available only on the basis of ability to pay? In a scale of health care priorities where would such a therapeutic intervention fit, if it were successful in achieving its therapeutic objectives 90% of the time? Would this be more important from the perspective of social justice than funding the development and dissemination of the TIAH, or some expensive anti-cancer therapy? [The therapies we have in mind here typically have costs of about \$50-\$100,000 for a course of treatment that yields anywhere from several extra weeks of life to several extra months of life.]

I have provided a very long list of issues here for several reasons. First, it is important to recognize the diversity and complexity of problems of health care justice that an adequate theory of health care justice must be able to address. Second, these problems are very often intimately connected to one another and require for their rationally justified resolution a fairly comprehensive vision of the domain of health care justice. For example, there may be some problems of justice connected with TIAHs that can be treated in a relatively isolated fashion, but there will be others complexly related to other problems of health care justice, i.e., where on a priority scale TIAHs are relative to funding embryonic genetic therapy, how many TIAHs a just and caring society is morally obligated to make available at shared expense, etc.

Third, our settled moral judgments in one area of health care justice, i.e., fair access to organ transplants, may become suddenly unsettled as a result of technological advances in that same area, i.e., the introduction of TIAHs. TIAHs are not (from a moral point of view) just another addition to our transplant armamentarium. They change dramatically how we need to think about the problem of justice with regard to organ transplants, certainly at the level of institutional and social policy. For now we can accept as tragic and unfortunate the limited numbers of transplantable organs that become available. There is relatively little we can do to change more than marginally that supply. But the development of artificial organs changes dramatically that aspect of the problem. There is no natural limit to the number of TIAHs that we could produce and implant. We might think that economic considerations or clinical judgment would create reasonable limits for

the dissemination of such technologies, but this would be a grievous moral mistake unless we had compelling arguments for the claim that such allocation mechanisms were most likely to yield a just (or just enough) distribution of these life-prolonging resources. I do not believe there are such arguments; and hence, we must face directly as a problem of health care justice the issue of how many TIAHs or other artificial organs (artificial livers are also in the works, analogous to dialysis) a just and caring society must make available.

Fourth, picking up on our Deweyan theme again, emerging problems of health care justice will constantly reflect back on our theoretic framework and force significant revisions in that framework (constitutional principles of health care justice). For example, we may have a reasonably settled sense of what commitment to protecting fair equality of opportunity means with respect to the problems of health care justice, until something like embryonic gene therapy comes along. Then the precise meaning and application of that principle may be revised in the light of the concrete judgments of justice we are motivated to make with respect to embryonic gene therapy in general (or very specific applications of that therapy). On this latter point it is easy to imagine that we would be intuitively inclined to support as a matter of justice embryonic gene therapy aimed at eliminating/ replacing genes linked to diseases and disorders that virtually all would agree seriously undermined an individual's capacity to function in what Daniels refers to as "the normal opportunity range." By way of contrast, we might also be strongly opposed to (perhaps as a matter of justice) embryonic gene therapy aimed at enhancing certain socially desirable traits, even if (perhaps most especially if) this were left as a matter of private pay and private markets. [There are some extraordinarily complex moral and political issues that come together under the heading of "genetic enhancement and health care justice." This will be one example of what I refer to as the "liberalism problem" of health care justice. The interested reader might consult a recent volume by John Harris, Enhancing Evolution: the Ethical Case for Making Better People (Princeton University Press, 2007).

I now want to return to the concept that initiated this last discussion, namely, the notion of public reason. I said that there are theoretical and practical dimensions to this notion. We can put this in another way. There is an ideal of civic discourse that we need to articulate. It is by no means unique to health care policy, but this is a policy area where such discourse is especially crucial because, as a central moral thesis in this book, we argue that just health care rationing policies and protocols must be self-imposed through social decision making mechanisms. Those social mechanisms must be governed by public reason. We might be inclined to think of public reason in its theoretical mode as achieving justified results through reflective equilibrium and public reason in its practical mode as yielding legitimate results through rational democratic deliberation. But that in fact is an indefensible dualism. The rationality of rational democratic deliberation is, at least in part, determined by the degree to which such deliberations seek to attain or maintain reflective equilibrium. In turn, in the real world of concrete policy decisions, and even with respect to what I refer to as our constitutional principles of health care justice, reflective equilibrium alone will not yield full justification. For that we need a reflective equilibrium

that has been democratically legitimated. [There is an interesting intersection here of Rawlsian and Habermasian perspectives that needs to be more fully explored.]

At the theoretical level the challenges are indeed daunting. I start with the proposition (for which I have argued in earlier papers) that the problem of justice in health care should be thought of as a problem of "health care justice." That is, we should think of "health care justice" as a distinct "sphere of justice" in something close to the way in which Walzer uses that latter phrase. This means that we cannot reasonably hope to solve the problems of health care justice by simply applying one of the grand theories of justice (Rawls or Nozick) to the particular issues of resource allocation found in our health care system. Norman Daniels is probably the first philosopher to come to this realization, and I follow him on this point.

Daniels has done more work than any other philosopher in articulating a theory of health care justice. (Menzel would be a close second; but after that we find a number of philosophers mostly writing individual articles and essays that address sketchily at best health care justice at a theoretical level. Securing Access to Health Care, Vols. II and III, would probably be the best single source of such early essays.) Daniels built on Rawls' early work to articulate his "fair equality of opportunity" account of health care justice. This is a solid piece of work, but Daniels himself readily admits today that this account is at best a very partial account of what a theory of health care justice needs to be. There are enormous numbers of health care justice problems, especially with regard to health care rationing, that are not effectively moved toward resolution by his fair equality of opportunity account. [See Daniels' 1993 Bioethics essay]. Hence, what is needed is a much more complex account of health care justice that speaks to the heterogeneity of health care justice issues that are part of our policy environment and that are occasioned by changing organizational structures in health care, such as the emergence and dominance of managed care organizations over the past ten years. Again Daniels has provided us with a very helpful model for thinking about these sorts of changes from a health care justice perspective [See his 1997 essay in *Philosophy and Public Affairs* "Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers."].

Menzel has probably done more work than any other philosopher in addressing the problem of health care rationing from a moral point of view. His major contribution is what is usually referred to as his theory of prior consent. This is a very important insight, which you see I build on in the seven propositions above. However, Menzel has what I would characterize as libertarian leanings, not as strongly defined as those of Engelhardt, but still a fair characterization when it comes to problems of health care justice. Consequently, unless social policy/social justice problems with respect to health care rationing can be dissolved as "social policy" [public interest] problems and recast as mere aggregation-of-individual-preference problems, Menzel's "prior consent" theory will not be adequate to the challenge. Hence, what is needed is an account of rational democratic

deliberation with respect to the problem of health reform and health care rationing that is truly democratic [put negatively, this means that just judgments with respect to health care rationing will not be merely a result of some deductive process; put positively, these judgments will be a product of genuine democratic conversation and policymaking processes] and that also yields results that are congruent with a morally defensible account of health care justice. [NOTE: I use the phrase “truly democratic” above to refer to a deliberative conception of democracy, which I would argue with Cass Sunstein and others represents the most morally and politically significant core of what democracy is about. I reject the view of those political scientists who see democratic processes as simply being the political analogue of markets, i.e., a political device for aggregating preferences that are already there. Deliberative democratic processes are essentially normative in function, aiming to shape our political judgments to better reflect or construct or specify in a more refined way the deep values endorsed by our society. Over the past several years, however, there has been vigorous debate about the virtues and vices associated with rational democratic deliberation. We will want to assess some range of these concerns. Sunstein himself has raised some of these in his work in the past several years.]

There is another way of describing the "Just Caring" problem and the theoretical challenges that it poses. This is in terms of eight large moral problems very intimately connected to the problem of health reform and health care rationing. Some of these challenges will be attacked directly in one or another seminar session. Others will be treated more thematically and require our revisiting them many times over the course of the seminar.

First, there is what I refer to as "the problem of pricing human life." This is absolutely central to understanding the current health reform/ health rationing debates. The problem can be put this way: How can a "just" and "caring" society allow individuals to die prematurely or suffer needlessly when we have the technological capacity to save those lives or alleviate that suffering but we fail to make that technology available to these individuals because it is unaffordable at the individual level and "too expensive" from a societal and/ or organizational point of view? The assumption implicit in the asking of this question is that human life is priceless, that no one should be allowed to die when we have the capacity to save or prolong their lives (and they want to live) "merely because of money." The argument continues:

It is one thing, morally speaking, to allow individuals to die because a certain life-saving good is absolutely scarce, such as a transplantable heart. Deaths like that are tragic, regrettable and unfortunate, but they are not morally criticizable so long as fair allocation rules determined who got the scarce life-saving good. But money is not something that is absolutely scarce, certainly not in our society. Hence, when we allow people to die merely because of money, we are putting a price on their lives. We are, in effect, saying that there are some lives that are not worth saving. This

violates the respect that ought to be accorded to the infinite worth of each and every human life. Each and every human life should be regarded as being priceless.

I reject this conclusion, and I argue in our second seminar session (as I did earlier in a 1990 essay) that the "pricelessness of human life" thesis is both morally incoherent and morally insidious. I argue that there are some lives that we (as a society, as a hospital, as a managed care plan, as health care providers) are not morally obligated to save; and further, that in failing to save those lives we are neither unjust nor uncaring. But then this leaves us with this theoretical (and ultimately practical) challenge: How do we decide justly and caringly which lives we are morally obligated to save (or reduce suffering or address other medical problems) and which lives we are morally permitted to allow "premature" death (or increased risk of death, or unrelieved suffering, etc.)? We need a deep account of health care justice that can address this challenge (though, again, justice is not the only moral concept that has relevance for addressing this issue). More recently, this issue has gotten concretized as the "last chance therapy" problem (which I addressed at length in a 2002 essay of mine). A real world case I will introduce from two years ago is the case of Dr. Michael DeBakey, an extraordinarily distinguished heart surgeon, who at age 98 underwent surgery to save his life that ultimately cost more than one million dollars. Did he have a "just claim" to that million dollars? Would we have been unjust as a society if we had refused to approve any social resources for that surgery? That was clearly a "last chance therapy" for him.

This brings us to our second major theoretical challenge. I will refer to it as the "just needs identification/ just prioritization" problem. I start with the assumption that what makes a moral claim on us as a society are health care needs, as opposed to health desires or health preferences. This suggests that we must have some sort of theoretical account of what will be correctly identified as a health care need. Daniels attempts to address this issue through his fair equality of opportunity account of health care justice. But as Daniels himself recognizes, and as Callahan has repeatedly emphasized in his recent writings [What Kind of Life and Setting Limits: Medical Goals in an Aging Society], health care needs are quite literally endless. This can be true at two levels. At the societal level emerging medical technologies are what contribute to the endless expansion of the domain of medical needs. At the individual level there is what Daniels (and others) refer to as the "bottomless pit" problem, individuals who have seemingly endless health care needs, for whom there are always more things we can do medically that may yield very, very slight benefit at enormous societal expense. These individuals do really have enormous health needs, but in a world of limited resources their needs can only be met at the expense of failing to meet someone else's needs. If these were relatively rare cases [extraordinary rescue of individuals cases], then this would minimize the moral gravity of the problem. But the fact of the matter is that what used to be acute, fatal medical problems are increasingly transformed into very long term, expensive chronic problems as a result of advancing medical technology [renal dialysis being an early and paradigmatic example of the phenomenon I have in mind here; cancer, heart disease and AIDS providing more

recent examples, as with the introduction of protease inhibitors, more recently fusion inhibitors]. The upshot of this is that a just and caring society cannot reasonably hope to meet all medical needs. If, however, a just and caring society is only going to meet some medical needs, then we need a strong theoretical account as part of our theory of health care justice that will justify our choosing to meet some medical needs rather than others. This is what I refer to as the "just prioritization" problem. Again, Daniels concedes that his own account fails to address adequately both the bottomless pit problem and the prioritization problem. In the real world Oregon is well known as having attempted to address the prioritization problem in its Medicaid program; and Oregon has endured severe criticism for its efforts, the implication being that Oregon got the prioritization problem wrong. If that is correct, then what would it mean to "get it right"? In a 1994 paper of mine [Journal of Medicine and Philosophy] I identify 11 key moral lessons that can be learned from Oregon's efforts. We might see this as a beginning to meeting the second theoretical challenge of coming up with a theoretical account of just health care needs and the just prioritization of those needs.

Our third theoretical challenge emerges from the second and might be referred to as the challenge of creating and preserving just liberal social policies with respect to health reform and health care rationing. The source of this challenge would be strong and moderate libertarians, such as Lomasky, Engelhardt, and Menzel, respectively. The challenge can be framed in these terms:

It is incredibly arrogant and illiberal and unjust (violative of individual liberty rights) that society [some assemblage of government bureaucrats and/ or business leaders] would determine for all individuals in that society what will count as a health care need and what the relative importance of those health needs might be. Individuals ought to be given the freedom to make these judgments for themselves. A liberal society cannot claim to have some comprehensive vision of the good or the just that should profoundly shape social policy. A pluralistic liberal society, such as our own, must recognize that there are numerous competing comprehensive doctrines and associated value schemes that individuals might adopt for purposes of leading what they judge to be a good life. A truly liberal society must remain neutral with respect to these competing comprehensive doctrines and allow individuals to make choices for themselves about how best to lead their lives.

A liberal society must not use its coercive powers to impose through social policy some scheme of values on unconsenting individuals, especially as regards the often very private and very personal sorts of decisions characteristic of health care. Some states, for example, provide quite generous Medicaid benefits for the poor; but [Menzel would argue] what if the poor themselves would prefer to have a less generous package of Medicaid benefits [no organ transplants, for example] so that they could use that money instead to meet what they would judge to be important non-health needs? Why should the middle class have the moral and political right

to impose their health care preferences on the poor? There is nothing about that that is either just or caring. If the middle class really did respect the rights to autonomy of the poor, then the middle class would provide the poor with cash grants for meeting what they themselves would judge to be their most important needs, health or otherwise.

Similarly, there are numerous incompatible religious views in our society that often result in incompatible attitudes with respect to advances in medical technology. If we were to have some form of national health insurance, i.e., a basic package of health services guaranteed to all in our society as part of our understanding of what was required of a just and caring society, then we would have to decide whether abortion services were included, or physician-assisted suicide, or various kinds of pre-natal genetic testing and/or genetic manipulation/embryonic selection, or various new approaches to addressing infertility problems, etc.---all of which would likely elicit strong objections from various religious groups, none of whom would have to accept such services, but all of whom would be financially contributing to supporting this system. On the face of it, an outcome like this seems to be illiberal and unjust and uncaring.

The obvious response to this challenge is to modify health policy in a way that would permit individuals as individuals to make their own choices with respect to health services/ health care priorities/ health care plans so that those choices were compatible with their most important personal values. This might be accomplished by giving everyone in our society a health care voucher or medical savings account that would have a societally agreed upon dollar value that could then be used to purchase any of a variety of health plans/ health insurance policies. For the moment we will pass over the obvious concern of the libertarian with how social resources [taxes] would be aggregated to bring this about. We will simply assume that sufficient social beneficence can be generated to achieve this objective. But that will still leave us with enormous problems. If we all had roughly the same health needs, then a system like this might work well enough so far as justice and liberality were concerned. But the fact is that there is enormous heterogeneity and unpredictability of need among individuals for any given year as well as for any individual across the span of a lifetime. In any given year, for example, 5% of our population is responsible for 54% of total health expenditures. If the value of a voucher and/ or medical savings account is set at some average level, then it will be obviously inadequate to meet the disproportionate health needs of this 5% of the population. Many of these individuals, of course, will know at the time they buy into a health plan/ health insurance group that they have such needs because they are afflicted with expensive chronic medical problems. Presumably this same knowledge would be available to plan managers/ insurers, who would be economically motivated to exclude such individuals from their plans. For the moment let us put aside for-profit plans. Imagine instead that all the members of this not-for-profit plan agreed among themselves that they wanted very affordable access to

excellent health care. Hence, they wanted to exclude from their plan anyone with serious, costly on-going health problems. They asserted as grounds for doing this a right of free association: the very healthy and likely healthy should be permitted to restrict their associational ties for insurance purposes to those who were like themselves. Is a liberal just and caring society politically obligated to acquiesce to such a free sorting of individuals? Or are there resources within liberal theory that would justifiably block such a sorting of individuals?

A fourth challenge is one raised by Daniels, which he refers to as the “Fair chances/ Best outcomes” problem. This is a problem, again, that occurs at all allocation levels (micro to macro), and in innumerable rationing contexts. Broadly stated, the problem is: Do we give everyone with the relevant medical need an equal chance of obtaining some scarce or expensive life-saving/ life-prolonging resource (the assumption being that this is the fair way of giving equal respect and consideration to all); or do we give priority to those who are likely to benefit the most from their having access to this medical resource? If one individual is likely to survive no more than two years from access to a liver transplant, and another individual is likely to survive at least ten years from access to that same transplant, then do we get a fairer outcome by flipping a coin between them (fair chances), or do we get a fairer outcome by maximizing the number of life-years saved (best outcomes)? Sometimes it seems justice is best served by maximizing outcomes, and at other times “fair chances” seems morally preferable. Do we have any satisfactory theoretical account as to when we ought to lean one way or the other? That is the challenge Daniels claims needs to be addressed in some theoretical fashion, lest the decision in any given instance become arbitrary or self-serving.

Fifth, there is the “ragged edge” problem that Callahan (1990) has identified. In short, it is that there are indefinitely distinguishable degrees of failing hearts and failing kidneys for which essentially the same treatment will be available but with results that will range from minimally to extraordinarily beneficial. The critical moral problem raised by these ragged edge examples is: How can we justifiably create sharp moral edges for health care rationing when there are only these very ragged edges in reality? In the world of law we do in fact create such sharp bright lines all the time. We pick age eighteen as the age at which individuals have the right to vote, or age twenty-one as the age at which individuals may legally consume alcohol. But such arbitrary bright lines do not seem to raise any serious moral problems because the consequences for individuals seem to be quite minor. By way of contrast, the expectation is that access to an artificial heart will yield an average increase in life expectancy of five years for an individual. If this were to be a Medicare covered benefit, we might attempt to control potentially extremely high increases in Medicare costs associated with availability of this device by insisting that an individual have a predictable increase in life expectancy of five years in order to have access to this device. But then what should a just and caring society do if a 71-year old individual has both advanced heart disease and an incurable cancer? The heart disease will cause his death within a few months (at most); the cancer will cause his death most likely in the next

two to three years. He very much wants those extra life years, perhaps hoping there will be some sort of medical breakthrough for his cancer as well. Is he treated unjustly if he is denied access to the artificial heart? Or is there any other deep moral value that would be violated by a denial of access to the artificial heart in these circumstances?

Sixth, there is what a number of writers have referred to as the “Rule of Rescue” problem. This is also sometimes referred to as the “identified life vs. statistical life” problem. We [society] allow literally thousands of individuals to die, as a result of automobile or other such accidents, because the cost of effectively preventing those deaths would be exorbitant. We comfort ourselves by thinking that these are all statistical lives that become identifiable lives only after the fact. By way of contrast it seems indecent and inhumane that we would allow identified individuals to die when we have the capacity to rescue them, though at very great cost. This is a common and recurrent problem. Oregon garnered considerable unwanted media attention when an eight-year old boy named Coby Howard was denied the transplant he needed to have a chance for prolonged survival. This was through their Medicaid program, whose administrators argued that there were other higher priority, more just claims to those limited medical resources that would be met by denying Coby Howard the transplant. But those “others” were merely statistical others (without names, without faces) for whom the critical public could muster little sympathy and even less a sense of justice. Many will also remember the Lakeberg conjoined twins who were born sharing a six-chamber heart. Though there was less than a 1% chance that either would survive, many in our society were outraged that Loyola Medical Center refused to do the surgery, in part because the cost of the surgery would have to come from hospital charity care dollars that administrators believed were better used to address other unmet health needs of the poor where there was near certainty that such needs would be successfully met. Both these cases garnered national media attention, but the more salient moral point is that this sort of scenario has been repeated thousands of times over, usually at a more local level. The moral challenge raised in all these cases is whether fair rationing protocols ought to be abrogated in such circumstances in order to attempt a rescue of an identified individual faced with death. That is, do such identified individuals make a different and stronger moral claim on us that would justify suspending normally fair rationing rules and procedures in order to meet their needs? Some of Peter Ubel’s work will help us think through this issue. See his book [Pricing Human Life](#).

The seventh broad challenge we need to face pertains to what Robert Veatch refers to as “slice-of-time” justice considerations and “course-of-life” justice considerations. In short, the issue is: How do we know when a particular problem of health care justice/health care rationing should be viewed from a ‘slice-of-time’ perspective as opposed to a “course-of-life” perspective? If we have two individuals, roughly the same age (45), roughly the same prognosis if they have access to an ICU bed, and if one of those individuals has already had more than 400 ICU days (because of serious chronic health problems over the course of the past ten years) but the other individual has never spent a day in the ICU, and if we have only one ICU bed available, then does the individual who

has never spent a day in the ICU have a stronger just claim to that bed, appealing to a course-of-life conception of justice to justify this allocation? Or is it the case that past ICU usage should be entirely ignored as morally irrelevant so that the allocation problem is then addressed from a slice-of-time perspective only? However we think about this first case, should we apply the same principle to this second case. We have two individuals, roughly the same age, roughly the same prognosis, both in need of a liver transplant to save their lives, only one liver available, virtually certain death for whichever individual does not receive the transplant. The difference between the two individuals is that one of them has already had a liver transplant, which is now failing. (We could say he had the transplant a year ago; we could say he had the transplant five years ago.) Should “course-of-life” justice considerations be used to address this problem, or should this case be viewed as a “slice-of-time” justice problem?

The eighth challenge to our conception of health care justice is what Daniels (1993) refers to as the “democracy problem.’ In brief, if we believe that we do not have the theoretical resources to solve every problem of health care justice “all the way down,” if we say that it is morally appropriate that democratic procedures be used to solve some of these problems ‘the rest of the way,’ then what sort of theoretical account can we give for distinguishing justice problems that must be non-democratically addressed from those that are justifiably left to democratic determination? Further, can we ever imagine circumstances in which we would be morally warranted in challenging the outcome that resulted from some democratic procedure; and, if we do, does that mean that we were not justified in making that democratic appeal in the first place?

## TOPIC SCHEDULE

### I. PRICING HUMAN LIFE: THE PROBLEM OF ESCALATING HEALTH CARE COSTS/THE CHALLENGES TO HEALTH CARE JUSTICE

This first session should be thought of as a "big picture" session. If we are going to be serious about doing applied philosophy, then it is imperative that you have at least a rudimentary understanding of the politics and economics and organization of our health care system. Without that understanding, the moral problems that we will be addressing will just not seem to have that much "bite" for you. If you have already had a course in medical ethics, then we think you will be able to appreciate this point more readily: If one knows very little about the actual practice of medicine, then it is that much more difficult to appreciate fully the nature and complexity of the moral problems that need to be discussed therein.

During much of the 1970s, judging at least from the published literature, it seemed that the widespread belief was that the moral problem with respect to health care policy was whether or not there was a "right to health care," the assumption being that if we could justify the existence of such a basic right, then we would know exactly what we had to do by way of coming up with morally acceptable health care policies. Usually it was assumed that if we adopted national health insurance then that would solve all the interesting moral problems so far as health care policy was concerned. What was taken for granted was that national health insurance would mean that everyone would get all needed health care. That, of course, fails to take into account the costs that would be associated with meeting needs of that magnitude---needs, which we shall discover, are enormously plastic.

Moreover, even if we avoid committing ourselves to national health insurance, a problem we are forced to face today is that of escalating health care costs: what may be done to control those costs? Who is responsible for bearing the burden of those costs? How much health care are we morally obligated to produce as a society? How strong is the correlation between more health care and better health? Something to note: Many health policy analysts will speak of two Great Equations in the field of health care. **EQUATION #1: Cost containment = Care Containment.** Controlling health care costs generally means reducing access to care for someone. It may be "only marginally beneficial" care, but that is still care, and in some circumstances such care will mark the difference between life and death. So this first Great Equation calls our attention to the *moral* dimensions of cost containment efforts. **EQUATION #2: Cost Containment = Income Containment.** Every time we control health care costs in some way we are also controlling [reducing] someone's income. This second Great Equation calls our attention to the central *political* problems associated with health care cost containment. All efforts to control health care costs will have redistributive effects with regard to someone's income, which will generally trigger intense political effort to prevent those re-allocations/ losses.

And then there is the whole problem of the heterogeneity of health needs, unlike our needs for food or clothing or shelter. The notion of a right to health care does nothing to address

any of the problems mentioned in the prior paragraph. Hence, what we shall argue is that we need instead to think about these problems from the perspective of justice, which we will use to generate very specific rights claims with respect to health care.

Near the beginning of this session we will do an analysis of the problem of escalating health care costs from a health policy perspective [as opposed to a moral or philosophic perspective.] This will be followed by an overview of health care cost containment strategies. This will set up nicely the first set of moral issues that we will need to address. For one response to efforts at health care cost containment is to insist that human life is priceless, that there is something morally despicable about the very idea of not making available the resources required to assure that all have access to needed health care, especially life-sustaining health care. We shall critically examine this alleged moral ideal of the pricelessness of human life and show it is not a feasible or reasonable or coherent ideal.

That will then lead to our next question: If we are not morally obligated to spend an unlimited sum of money to save or prolong a human life, then how much are we morally obligated to spend? And who is this "we" who might be obligated to spend some sum of money? Is it society at large? A local community? A managed care plan? A family? An individual? We then need to ask whether we must think of all lives as being of equal moral value and equally worthy of having some amount of money spent to save that life when necessary. Or would it be morally permissible to disaggregate a life and think of it in terms of remaining discrete "life-years"? Our earlier question then becomes: How much are we morally obligated to spend per life-year saved? This in turn yields a yet more refined question when we note the radically different qualities that might be associated with different life years and different medical circumstances. We can then introduce the concept of "quality-adjusted life-years" [QALYs], and ask how much we are morally obligated to spend per QALY? Needless to say, there is the prior moral issue of whether it is morally acceptable to think about human lives in quality-adjusted terms. Does such a conceptualization result in the mentally or physically handicapped being treated unequally and unfairly with respect to their access to health care? We will not try to address the QALY questions in this first class. These issues will become salient when we address the problem of prioritizing health care needs and the problem of determining the just health care claims of individuals with various disabilities.

**In terms of journals with which you ought to have familiarity if you are going to work in this area of philosophy, Health Affairs should be your first choice. This is the most widely read health policy journal for those who have those research or practical interests. Here is an example of the sort of article that appears there that is pertinent to this course.**

Borger, C., Smith, S., Truffer, C., Keehan, S., Sisko, A., Poisal, J. et al. 2006. "Health Spending Projections Through 2015: Changes on the Horizon." *Health Affairs* 25: w61-73.

Catlin, A., Cowan, C., Hartman, M., Heffler S. 2008. "National Health Spending in 2006: A Year of Change for Prescription Drugs." *Health Affairs* 27: 14-29.

Keehan, S., Sisko, A. Truffer, C. Smith S. et al. 2008. "Health Spending Projections Through 2017: The Baby-Boom Generation is Coming to Medicare." *Health Affairs* 27 (Web Exclusive): W145-W155

**You also need to be attentive to a range of medical journal articles that are the primary source (often) of the resource allocation/justice/ health policy issues we discuss in this seminar. Here are some examples.**

Kurella, M., Covinsky, K., Collins, A., Chertow, G. 2007. "Octogenarians and Nonagenarians Starting Dialysis in the United States." *Annals of Internal Medicine* 146: 177-83.

Knaus, W., Wagner, D., Draper, E. et al. 1991. "The APACHE III Prognostic System: Risk Prediction of Hospital Mortality for Critically Ill Hospitalized Adults." *Chest* 100: 1619-36.

Mitka, M. 2003. "Expanding Statin Use to Help More At-Risk Patients is Causing Financial Heartburn." *Journal of the American Medical Association* 290: 2243-45.

Stevenson, L. 2006. "Implantable Cardioverter Defibrillators for Primary Prevention Of Sudden Death in Heart Failure: Are There Enough Bangs for the Bucks?" *Circulation* 114: 101-03.

Sulmasy, D. 2007. "Cancer Care, Money, and the Value of Life: Whose Justice? Which Rationality?" *Journal of Clinical Oncology* 25: 217-22.

Bach, P. 2008. "Cost Sharing for Health Care---Whose Skin? Which Game?" *New England Journal of Medicine* 358: 411-13.

Wells, D., Ross, J. Detsky, A. 2007. "What is Different about the Market for Health Care?" *JAMA* 298: 2785-87.

Kuttner, R. 2008. "Market-Based Failure---A Second Opinion on U.S. Health Care Costs." *New England Journal of Medicine* 358: 549-51.

Waugh, N., Black, C., Walker, S., McIntyre, L., Cummins, E., Hillis, G. 2006. "The Effectiveness and Cost-effectiveness of computed Tomography Screening for Coronary Artery Disease: Systematic Review." *Health Technology Assessment* 10 (Oct.): 1-41.

**You also want to pay attention to the popular press, at least the more reliable members of that group, such as the New York times or Boston Globe or Washington Post etc. Here are some examples of material I have used in my book or other articles or in preparing for this seminar.**

Carreyrou, J. 2007. "Maxed Out: As Medical Costs Soar, the Insured Face Huge Tab." *Wall Street Journal* (Nov. 29): A1.

Altman, L. 2006. "The Man on the Table was 97, but He Devised the Surgery." *New York Times* (Dec. 25): A1.

Allen, S. 2007. "Critics Blast Slow Progress on Cancer: Say Costly Drugs do Little to Extend Lives." *Boston Globe* (Dec. 2): Nation section.

Anand, Geeta. 2003. "Who Gets Health Care? Rationing in an Age of Rising Costs." *Wall Street Journal* (Sept. 12): A1.

Appleby, J. 2002. "Hospitals Fight for Turf in Medical Arms Race." *USA Today* (Feb. 19): national news section.

Berenson, A. 2006. "A Cancer Drug Shows Promise at a Price That Many Can't Pay." *New York Times* (Feb. 15): Health section.

Blackwell, T. 2007. "Family Fights Hospital Over Father's Care: Lack of Treatment Violates Jewish Faith, Court Told." *The Financial Post (Canada)* (Dec. 11): A14.

Landers, P. 2003. "Who Gets Health Care? Rationing in an Age of Rising Costs."

*Wall Street Journal* (Oct. 2): at A1.

Matthews, R. G. 2003. "A Retired Steelworker Struggles with a Health-Insurance

Crisis." *Wall Street Journal* (May 12): at A1.

## READINGS

(A=required readings for all, B/C/D = required readings for each of those groups)

Bodenheimer, Thomas and Grumbach, Kevin. Understanding Health Policy: A Clinical Approach, 4th ed. (Appleton and Lange, 2004), 1-20.  
[This entire volume is an excellent introduction to the structure of our current health system and health policy.] [A]

Fleck, Leonard. Just Caring (2008): chapters 1 and 2 [A]

Ubel, Peter. Pricing Life: Why It's Time for Health Care Rationing  
Introduction (xii—xix) and chaps. 1-3, pp. 1-44. [B]

Menzel, Paul. Medical Costs, Moral Choices, (Yale University Press, 1983), chapters 1+2, pp. 1-55.

Brock, Daniel. "The Value of Prolonging Human Life," Philosophical Studies, 50 (Nov., 1986), 401-28. This essay is reprinted in Brock's collection Life and Death: Philosophical Essays in Biomedical Ethics (Cambridge University Press, 1993). [C]

Blank, Robert. The Price of Life: The Future of American Health Care (Columbia University Press, 1997).

Nord, Eric. Cost-Value Analysis in Health Care: Making Sense Out of QALYs (Cambridge University Press, 1999).

Veatch, Robert M. "Justice and Valuing Lives" in Lifespan: Values and Life-Extending Technologies, edited by Robert Veatch (New York: Harper and Row, 1979), 197-224. See also in this volume the two pieces by the Hastings Center Research Group, "Values and Life-Extending Technologies," 29-79; "Guidelines

for Research, Development, and Delivery of Life-Extending Technologies," 80-83.

Bayles, Michael. "The Price of Life," Ethics, 89 (October, 1978), 20-34.

Rhoads, Steven. "How Much Should We Spend to Save a Life?" in Valuing Life: Public Policy Dilemmas, edited by Steven Rhoads (Boulder: Westview Press, 1980), 285-311. In this same volume see also the article by Fred Hapgood, "Risk-Benefit Analysis: Putting a Price on Life," 313-24.

Agich, George and Begley, Charles (eds.). The Price of Health (Dordrecht: D.Reidel Publishing, 1986). There are a number of pertinent essays in this volume, which I would call to your attention:

Agich, George. "Economic Cost and Moral Value," 23-44.

Morreim, E. Haavi. "Computing the Quality of Life," 45-70.

Wenz, Peter. "CBA, Utilitarianism, and Reliance Upon Intuitions," 71-90.

Menzel, Paul. "Prior Consent and Valuing Life," 91-112.

Audi, Robert. "Cost-Benefit Analysis, Monetary Value, and Medical Decision," 113-33.

Zeckhauser, Richard and Shephard, Donald. "Where Now for Saving Lives?" Law and Contemporary Problems, 40(1976), 5-45. The entire issue of this journal is devoted to the moral and legal and public policy questions associated with pricing human life.

Fried, Charles. An Anatomy of Values: Problems of Personal and Social Choice (Cambridge: Harvard University Press, 1970), especially chapters 10 ["Life Plans and Mortality"], 11 ["Imposing Risks on Others"] and 12["The Value of Life"].

Harris, John. "QALYfying the Value of Life," Journal of Medical Ethics (with a response by Alan Williams), 13 (Sept., 1987), 117-23.

Rawles, John. "Castigating QALYs," Journal of Medical Ethics, 15 (Sept., 1989), 143-47.

Mooney, Gavin. "QALYs: Are They Enough? A Health Economist's Perspective," Journal of Medical Ethics, 15 (Sept., 1989), 148-52.

Bayles, Michael. "The Value of Life," in Health Care Ethics, edited by Donald VanDeVeer and Tom Regan (Philadelphia: Temple University Press, 1987), 265-89.

## **II. WHY IS HEALTH CARE "SPECIAL"?**

There are four large questions that we will begin to explore in this session. **(1) When we ask why health care is special, what we are really asking is whether health care should be distributed in accord with some set of moral norms.** That is, why should we not think of health care as being like any other consumer good or service? These are things distributed according to ability to pay. This does not seem to be cause for moral outrage among most citizens in our society. That is, we tolerate considerable disparities in wealth and income in our society. So why should we not similarly tolerate wide disparities in access to health care? What would make us think that there was anything especially unjust about the fact that sometimes some people did not get health care that they needed? The President's Commission will offer us one sort of answer to this question and Norman Daniels will offer us another. Engelhardt, as a libertarian, is going to be sceptical of the practical implications of the view of Daniels, for he will be anxious to protect the liberty rights of all participants in the health care system. He will be especially opposed to those who would use the coercive power of government to extract resources from the wealthy well to provide health care for the ill poor.

**(2) I will defend the view that *not ALL health care is morally special.*** This implies that some health care may be distributed on the basis of non-moral considerations, such as individual ability to pay. That in turn will raise the question of how we distinguish between health care that ought to be distributed in accord with some moral norm (such as justice), and health care that is permissibly distributed in accord with non-moral considerations. But I wish to put that question aside for now. **Instead, our second large question is: For whatever range of health care ought to be distributed in accord with a moral norm, what ought that norm be---justice or beneficence?** The President's Commission will say that all in our society ought to have access to an adequate package of health care services----and this is a matter of social beneficence. The Commission does claim that this is a matter of *obligation*, but it would also seem to be morally true that obligations of beneficence shade off into charity that is non-obligatory. No doubt there is political value attached to thinking in these terms. There is, it seems, a much greater range of flexibility and ambiguity with respect to what health care a good society is *obligated* to provide. Hence, as I argue in my book material in the readings, I will want to defend the view that there is a substantial range of health services that ought to be thought of as matters of social justice. (FYI: Allen Buchanan will argue that we don't really need to settle the question of whether we are talking about justice or beneficence; the central moral issue would have to do with the bounds of *obligation* in these matters.)

**(3) If there is some range of health care services that ought to be distributed in accord with some conception of health care justice, then what conception of justice should that be?** We can distinguish a strong egalitarian view [Veatch], a moderate egalitarian view [Daniels], a utilitarian view [Eddy, Gauthier], a libertarian view [Engelhardt], a very hybrid view maybe with a lean toward libertarianism [Menzel]. And then of course there is the role of rational democratic deliberation in getting more just distributions of health care [Fleck]. As I

indicated earlier, I do not believe that any one of these theories is really capable of addressing ALL the problems of health care justice. Instead, I will argue that for each particular problem of health care justice, it will be morally appropriate to address that problem *as if* one or another of these conceptions was most apt as a conception of health care justice. The philosophic challenge is to come up with an adequate justification in each case for saying that a just result with regard to *that* problem is most likely if we treat this as a “strong egalitarian” problem, or as a libertarian problem, etc. This large issue should be a major focus of seminar discussion.

(4) This brings us to our fourth large question. There is another perspective we need to take on our original question, namely, why we should think of health care as being special from a political perspective. **That is, what justifies government intervention (the making of public policy) in the health care system, through, for example, Medicare and Medicaid, or various efforts at health planning, or various efforts at health care cost containment? Why should not markets and competition determine how health services are distributed in our society, to whom, and at what price, especially if we want this accomplished in as efficient a way as possible.** If health care is thought of as a private consumer good, then all such government interventions will need some sort of political and moral justification. One way of answering this concern is to argue that health care (or at least some range of health services) represents a public good; it is a public interest. We need to ask what would justify this claim. Assuming this basic claim can be justified, the further question then is: How expansive should we consider the claim to be that health care is a public good? It seems obvious with respect to public health concerns, but then there is all the highly individualized health goods sought by individual patients. Are all of these properly thought of as public goods as well? Here is a passage from Engelhardt, a libertarian, which expresses a conflicting point of view: "The imposition of a single-tier, all encompassing health care system is morally unjustifiable. It is a coercive act of totalitarian ideological zeal, which fails to recognize the diversity of moral visions that frame interests in health care..." (p.375)

Rhodes, Battin, Silvers. Medicine and Social Justice: Essays on the Distribution of Health Care  
Essays by Daniels, Menzel, Blustein, Hayry, Wasserman, Baumrin, Hessler/Buchanan,  
pp. 1-96. [A]

Daniels, Norman. Just Health: Meeting Health Needs Fairly, 1-103 [A]

\*Daniels, Norman. "Health Care Needs and Distributive Justice," Philosophy and Public Affairs, 10 (1981), 146-79. Reprinted in Justice and Justification (Cambridge University Press, 1996), 179-207.

\*President's Commission for the Study of Ethical Problems in  
Medicine. Securing Access to Health Care, Vol.I (Washington,  
D.C.: Government Printing Office, 1983), 11-47. [C]

\*Engelhardt, Tristram. "Rights to Health Care, Social Justice, and Fairness  
in Health Care Allocations," in The Foundations of Bioethics  
second edition (Oxford: Oxford University Press, 1996), 375-410. [D]

\*Fleck, Leonard. "Just Health Care: Is Beneficence Enough?"

- Theoretical Medicine, 10 (June, 1989), 167-82.
- \*Wikler, Daniel. "Philosophical Perspectives on Access to Health Care," in Securing Access to Health Care, Vol.II, President's Commission for the Study of Ethical Problems in Medicine (Washington, D.C.: Government Printing Office, 1983), 109-51.
  - \*Gauthier, David. "Unequal Need: A Problem of Equity in Access to Health Care," in Securing Access to Health Care, Vol.II, President's Commission for the Study of Ethical Problems in Medicine (Washington, D.C.: Government Printing Office, 1983), 179-205. [B]
  - \*Buchanan, Allen. "The Right to a Decent Minimum of Health Care," in Securing Access to Health Care, Vol.II, President's Commission for the Study of Ethical Problems in Medicine (Washington, D.C.: Government Printing Office, 1983), 207-38. [B]
  - \*Brock, Dan. "Distribution of Health Care and Individual Liberty," in Securing Access to Health Care, Vol.II, President's Commission for the Study of Ethical Problems in Medicine (Washington, D.C.: Government Printing Office, 1983), 239-63. [C]
  - Harris, John. "What is the Good of Health Care?" Bioethics, 10 (Oct., 1996), 269-91. [Interesting paper; raises questions on conflict between respect for patient autonomy/ their conception of health benefits and justice/ allocation issues.]
  - Daniels, Norman. "Rights to Health Care and Distributive Justice: Programmatic Worries," The Journal of Medicine and Philosophy 4 (June, 1979), 174-91.
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  - Moskop, John. "Rawlsian Justice and a Human Right to Health Care," Journal of Medicine and Philosophy, 8(November, 1983), 329-38.
  - Stern, Lawrence. "Opportunity and Health Care: Criticisms and Suggestions," Journal of Medicine and Philosophy, 8 (Nov., 1983), 339-61.
  - Daniels, Norman. "A Reply to Some Stern Criticisms and a Remark on Health Care Rights," Journal of Medicine and Philosophy, 8 (Nov., 1983), 363-71.

### III. TRAGIC CHOICES AND THE PROBLEM OF INVISIBLE RATIONING

**In this class we will be examining the issue of whether or not the various forms of invisible rationing are morally justifiable. The larger question we are addressing in this and the subsequent class is: What conditions are necessary for making it more likely that we will make fair rationing decisions, whether at the level of individuals, institutions or public policies? The short answer I will defend in this class is that rationing decisions must be public, visible to those who are affected by them. The short answer I will give in the next class is that rationing decisions ought to be autonomously self-imposed. Rationing decisions that are imposed by some on others are presumptively unjust.**

What we mean by this notion of invisible rationing is that individual patients are denied access to needed health care without their being aware of the fact that such rationing has occurred. Invisible rationing is accomplished through markets (by price), but it also occurs under Medicare DRGs, in HMOs, and in the British National Health Service. Calabresi and Bobbitt have probably provided the most extensive defense of such practices from both moral and political perspectives. Their basic argument is that we are faced with tragic choices when we must make decisions about rationing access to health care, especially health care that will make the difference between extended life and death. The choices are "tragic" in a morally significant sense because no matter what we do we will end up violating some fundamental societal value. Either we will visibly "price human life" or we will violate basic requirements of justice. From their perspective the moral virtue of invisible rationing is that such tragic choices are accomplished outside the public purview, and in that way the moral fabric of society is not visibly destroyed. I will argue, however, that one of the core moral aspects of our conception of justice is what Rawls refers to as "the publicity condition," and that Calabresi and Bobbitt have not provided sufficient moral justification for overriding that element of justice.

The issue of invisible rationing probably arises most frequently within the context of managed care. This is because physicians are motivated by various financial incentives to control patient access to more expensive care within the plan. The incentives that are used (capitation, withholds, etc.) are largely unknown to patients who are being cared for by these physicians. Some will argue (Mechanic) that it would be a really bad idea for physicians to reveal such incentives (and consequent rationing decisions) to patients that are in the middle of receiving care from them. The effect would be to undermine trust in the physician, and this might prove to be anything but therapeutic for the patient. Better, Mechanic argues, that we should rely upon professional norms (and at least constantly implicit legal threats of malpractice) to constrain physicians from making cost-saving/ income-protecting judgments that could have seriously deleterious effects on patients. This would suggest that rationing decisions need not always be visible to patients. Mark Hall, for example, will argue that rationing/ cost control decisions within a managed care plan are sufficiently visible [satisfy the publicity condition] if patients are informed of such mechanisms when they join a plan. He contends that patients then have the opportunity to give "bundled consent" to whatever cost control mechanisms a particular

plan employs (and such consent will be morally sufficient (generally) for subsequent patient encounters, at least so far as justice is concerned. We will need to give careful attention to the claims of both Mechanic and Hall. **As you prepare for this session, ask yourself whether you agree or disagree with the arguments Calabresi/ Bobbitt provide in support of their “tragic choices” position. Then ask yourself whether you agree with Hall and Mechanic and their defense of implicit rationing. What sorts of considerations do you see as being morally relevant in thinking through these issues? What sorts of reasons would you give to support your view?**

Fleck, Leonard. Just Caring, chapter 3 (2008) [A]

\*Calabresi, Guido and Bobbitt, Philip. Tragic Choices, (New York: W.W. Norton, 1978), 17-50. [A]

\*Callahan, Daniel. “On the Ragged Edge: Needs, Endless Needs,” chap.2 of What Kind of Life: The Limits of Medical Progress (Simon and Schuster, 1990), 31-68. [D]

\*Fleck, Leonard. "Justice, HMOs, and the Invisible Rationing of Health Care Resources," Bioethics, 4 (June, 1990), 97-120.

\*Ubel, Peter. “The Politics of Defining Health Care Rationing,” chap. 2 from Pricing Life: Why It’s Time for Health Care Rationing (MIT Press, 1999), 11-30. [A]

\*Nelson, James. “Publicity and Pricelessness: Grassroots Decisionmaking and Justice in Rationing,” The Journal of Medicine and Philosophy 19 (1994), 333-42. [A]

\*Hall, Mark. “Informed Consent to Rationing,” chap.6 in Making Medical Spending Decisions: The Law, Ethics, and Economics of Rationing Mechanisms (Oxford University Press, 1996), 193-239. [A]

Mechanic, David. “Professional Judgment and the Rationing of Medical Care,” University of Pennsylvania Law Review 140 (May, 1992), 1713-54. [C]

Mechanic, David. From Advocacy to Allocation: The Evolving American Health Care System (New York: The Free Press, 1986), chapter three.

Baily, Mary Ann. "Rationing Medical Care: Processes for Defining Adequacy," in The Price of Health, edited by George Agich and C.E. Begley (Dordrecht: D. Reidel, 1986), 165-84.

Friedman, David. "Comments on 'Rationing Medical Care: Processes for Defining Adequacy,'" in The Price of Health, op. cit., 185-97.

Winslow, Gerald. "Rationing and Publicity," in The Price of Health, op. cit., 199-215.

- Friedman, David. "Comments on 'Rationing and Publicity,'" in The Price of Health, op. cit., 217-24.
- Blumstein, James. "Rationing Medical Resources: A Constitutional, Legal and Policy Analysis," in Securing Access to Health Care, Vol. III, The President's Commission (Washington, D.C.: Government Printing Office, 1983), 349-94.
- Rosenblatt, Rand. "Rationing 'Normal' Health Care: The Hidden Legal Issues," in Securing Access to Health Care, Vol. III, op. cit., 395-411.
- Povar, Gail and Moreno, Jonathan. "Hippocrates and the Health Maintenance Organization: A Discussion of Ethical Issues," Annals of Internal Medicine, 109 (Sept., 1988), 419-24.
- Halper, Thomas. The Misfortunes of Others: End-Stage Renal Disease in the United Kingdom (Cambridge: Cambridge U Press, 1989), ch.3.

#### **Additional background reading suggestions:**

**The second edition of the book that in 1984 really got the “invisible rationing” debate going is titled Can We Say No? the Challenge of Rationing Health Care by Henry Aaron and William Schwartz (2005). The book provides some nice comparisons between the US and the UK on matters of health care rationing. Especially interesting is to see how things have changed or not changed between 1984 and 2005.**

**The initial discussion of the “publicity condition” comes from John Rawls in A Theory of Justice. Rawls explicates that much more fully in Political Liberalism, especially chapter two. This is also closely related to the notion of “public reason” which is the heart of what rational democratic deliberation is about. It would be good to have some familiarity with this work of Rawls. I would also call your attention to Samuel Freeman, who is a prolific and reliable interpreter of Rawls’ work. There are three books with which he is associated. A comprehensive overview of Rawls work is Rawls (Routledge, 2007). A collection of essays by Freeman on major aspects of Rawls’ work is Justice and the Social Contract: Essays on Rawlsian Political Philosophy (Oxford, 2007). Freeman is also the editor of the Cambridge Companion to Rawls (Cambridge University Press, 2002).**

**As for Calabresi and Bobbitt on the issue of “pricing human life” [the very broad issue of what social risks a just and caring society with limited resources ought to tolerate] you could read this article by Gregory Keating, “Calabresi’s the Costs of Accidents: A Generation of Impact on Law and Scholarship: Pricelessness and Life: An Essay for Guido Calabresi,” *Maryland Law Review* 64 (2005), 159-219. I will mention in passing that law journals are often useful resources for thoughtful essays on many of the topics we will address in this course. You should have some familiarity with them.**

#### **IV. HEALTH CARE RATIONING: WHO SHOULD MAKE JUST AND RESPONSIBLE RATIONING DECISIONS?**

This class is really a continuation of the prior session. As this class unfolds we will see that there are numerous dimensions to the rationing issue we will need to consider. (1) As noted already, the short answer to the question of who should make just and responsible rationing decisions is each of us as autonomous agents. This is a rejection of the idea that “others” should make those decisions for us.

(2) When should autonomous agents make rationing decisions? It would seem that if our objective is both to save money (purchase only costworthy health care) and preserve justice (given limited resources and virtually unlimited health needs), then it is unlikely we could achieve either of these objectives if individuals were supposed to make rationing decisions when they were in the midst of health crisis, or had some sort of significant health need they hoped would be met. It would be too easy and too tempting for individuals at that point in time to favor their own health interests at the expense of others. So both David Eddy and Paul Menzel will argue that these decisions have to be a matter of “prior consent.” That is, these decisions have to be made long before someone is in the midst of health crisis, perhaps at the time someone joins a health plan of some sort. Also, the point of view one must adopt for making such decisions fairly must have some comprehensive and impartial and rational quality to it. David Eddy will speak of taking the point of view of a “Patient” with a capital ‘P.’ That “Patient” represents all the possible health needs [possible healthy/ unhealthy selves I might be] I might have in the future (given that generally, all of us are very much like Rawlsian agents behind a veil of ignorance when it comes to our future health needs). This suggests we will make some trade-offs, establish some priorities with respect to our meeting our future health care needs.

(3) That brings us to the next large issue. What exactly constrains or shapes the sorts of decisions I make? The short answer is obviously that it is my budget. Does that mean I am actually limited by my own personal ability to pay, or the willingness of my employer to pay for some range of health services? If that is the case, then it seems we have no assurance that individuals will receive all the health care to which they have a just claim. It seems we need some objective, or objective enough reference point, for determining what level of health services will be guaranteed to all----the language used most often being “adequate,” “basic,” “basic minimum,” “essential,” “reasonable,” “costworthy,” or “medically necessary.”

(4) Is it really possible for me to make the sort of self-imposed rationing decisions Eddy and Menzel envision ‘all by myself’? Or must this enterprise necessarily be a collective effort? And, if so, what should this collective effort look like? There are times, I think, when Eddy seems to believe that this “PATIENT” really is ‘everyman’ or ‘every rational agent.’ In other words, we would all make the same decisions; we would all recognize clearly and distinctly what was or was not costworthy health care----the numbers would just make that self-evident. This is Eddy speaking as an economist rather than as a physician or patient. We will need to critically explore this claim.

(5) How are our rationing commitments best expressed and realized? Should they be expressed in the form of centrally created and administered rules? Problem: How can such rules

be sensitive to all the complexities and uncertainties and individual health idiosyncracies associated with the actual practice of medicine? Better, Mark Hall, will argue that we rely upon “incentives” to generate health care decisions that are fair, cost-effective and medically appropriate. These incentives, of course, are not directed at patients for the most part (though some can be, and that will raise important moral problems), but more often these incentives are directed at physicians caring for patients, thereby generating the phenomenon known as ‘bedside rationing,’ which is seen as both a threat to the integrity and trustworthiness of physicians and a threat to the overall fairness of a system of rationing. NOTE: In this connection I will call your attention to a new book I recently read titled Nudge: Improving Decisions about Health, Wealth and Happiness by Richard Thaler and Cass Sunstein (2008). It is a provocative and entertaining piece of writing, certainly worth your time five years from now after you have completed all the other reading for this seminar.....don’t you just hate professorial humor like that???? The authors defend what they call a paternalistic libertarian strategy as a middle road for addressing some range of social policy issues. Neither is an ideologue; both write very well.

#### READINGS:

Fleck, Leonard. Just Caring, chapter four (2008) [A]

Daniels, Norm. Just Health, chap. 4, pp. 79-103.

Menzel, Paul. Strong Medicine, pp.3-56 [C]

Elhauge, Einer. “Allocating Health Care Morally,” California Law Review, 82 (Dec. 1994) 1449-1554. [A]

Eddy, David. “Connecting Value and Costs: Whom Do We Ask, and What Do We Ask Them?” “Rationing by Patient Choice,” “What Care is ‘Essential’? What Services are ‘Basic’?” “The Individual vs. Society: Is There a Conflict?” “The Individual vs. Society: Resolving the Conflict,” all reprinted as chapters in Clinical Decision Making: From Theory to Practice (Jones and Bartlett, 1996), 77-120. [A]

Rai, Arti. “Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care,” Indiana Law Journal, 72 (1997), 1015-97. [B]

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Farrelly, Colin. “Justice in Ideal Theory,” forthcoming in *Political Studies* (2008).

Ubel, Peter. “How Do People Want to Ration Health Care? Balancing Cost-Effectiveness and Fairness,” in Pricing Life: Why It’s Time for Health Care Rationing (MIT Press, 2000), 47-95. [A]

Mechanic, David. “Muddling Through Elegantly: Finding the Proper Balance in Rationing,” Health Affairs, 16 (1997), 83-92. [A]

Buchanan, Allen. “Rationing Without Justice, but Not Unjustly,” Journal of Health Politics, Policy and Law, 23 (Aug., 1998), 617-34. [A]

## **V. JUST HEALTH CARE RATIONING: A RATIONAL DEMOCRATIC DELIBERATIVE APPROACH, PART I**

This will be one of the sessions in this course where we try to achieve some theoretical integration that also has practical relevance. The major claim that I will want to defend is this: Health care rationing is most likely to be fair if it is the case that it is self-imposed rather than imposed by someone else. What I will reject is the libertarian interpretation of this claim which would simply allow individuals as individuals to make these decisions for themselves. Instead, I will want to defend what I take to be a position congruent with the more recent Rawls of his book Political Liberalism (1993). Since it is collective decisions that are necessary (to a large extent) when it comes to health care rationing (within what I will refer to as the domain of health care justice), this means that it ought to be through public, visible, comprehensive, informed democratic conversations and processes that this is accomplished. This claim is intended to cover rationing decisions within managed care organizations, state Medicaid programs, the federal Medicare program, and any morally defensible form of cost-effective national health insurance. To connect this discussion with current policy debates, libertarians tend to be advocates of Medical Savings Accounts [MSAs] as a mechanism for accomplishing highly individualized health care rationing. I will argue that that idea in its various forms is seriously flawed from the perspective of health care justice that I defend.

Our major objective in this session will be to critically assess the specific model of rational democratic deliberation I defend. (1) My general claim is that rational democratic deliberation represents a fairer approach to health care rationing than any other general approach. Do you agree? (2) As noted early in the course, I wish to defend a pluralistic account of health care justice. This is captured in my notion of a series of "constitutional principles of health care justice" that define the "moral space" of just health care rationing. Questions: Is this notion of constitutional principles of health care justice a useful and theoretically sound notion? I do not award lexical priority to any of these principles. Is this a theoretical flaw or a theoretically defensible practical advantage of my account? [Part of what I shall want to argue is that lack of lexical priority among the principles creates a kind of moral and political "wiggle room" that can permit a workable overlapping consensus to emerge with respect to these principles as a whole. I see this as a definite moral, practical, and political advantage.] Do I have the "right number" of principles? Are there some that might be missing? Are there some that are redundant or that ought to be subsumed under others? Compare what I propose to what Gutmann and Thompson propose in their book Democracy and Disagreement, also paying attention to some of the critical essays I have provided to you that represent commentary on that book.

(3) I will want to argue that Rawls' notion of wide reflective equilibrium can provide us with the degree of theoretical rigor and consistency that we need to prevent these principles from being applied in arbitrary ways. Am I correct in that belief and my account of how that would work? Note: The reflective equilibrium among the principles would be sought primarily with respect to very specific problems of health care justice/ health care rationing, such as we will be

discussing in the latter part of the course. At best, I will argue, there is no more than a very general sort of reflective equilibrium among the constitutional principles of health care justice in the abstract. NOTE: One of our main tasks in the remainder of the course is to refine the specificity of those constitutional principles of health care justice through applying them to specific problems of health care justice (in much the same way, I believe, as our own constitutional principles are refined, re-balanced, adapted, reinterpreted in response to novel policy challenges that emerge in our society).

(4) One of the main purposes of my account of these principles of health care justice is to define the space of health care justice so that we can see more clearly what sorts of health care services/ interventions are "beyond justice," that is, are matters of beneficence or free markets or some other distributive mechanism that cannot be criticized from the point of view of health care justice. The critical question is whether my account gets that distinction about right. That is, could I be justifiably accused of having drawn the boundaries of the domain of health care justice either too broadly or too tightly? There are a number of objections that may be raised to the position that I seek to defend here, most cogently by Norman Daniels ["Rationing Fairly," see below]. I attempt to respond to his objections in some new essays that I have written, and that I will share with the seminar group.

Fleck, Leonard. Just Caring (2008), chapter 5 (posted on ANGEL) [A]

Fleck, Leonard. "Just Caring: Health Care Rationing and Rational Democratic Deliberation," outline of NIH seminar paper (March, 1999).

Fleck, Leonard. "Just Health Care Rationing: A Democratic Decisionmaking Approach," University of Pennsylvania Law Review, 140 (May, 1992), 1597-1636. [This entire issue is a symposium issue on health care rationing.]

Fleck, Leonard. "Just Caring: Oregon, Health Care Rationing, and Informed Democratic Deliberation," Journal of Medicine and Philosophy, 19 (1994), 367-88.

Fleck, Leonard. "Rational Democratic Deliberation: Meeting the Challenges of Justice and Health Care Rationing," paper presented at APA Pacific Division Meetings (1995).

Daniels, Norman. "Rationing Fairly: Programmatic Considerations," Bioethics, 7 (Jan., 1993), 224-33. You have the version of this article from Daniels' book Justice and Justification. [A]

Rhodes, R. 2005. "Justice in Medicine and Public Health." *Cambridge Quarterly of Healthcare Ethics* 14 (Winter): 13-26. [A]

Fishkin, James and Laslett, Peter (eds). Debating Deliberative Democracy (Blackwell, 2003). There are a number of very good critical essays in this volume.

- Amy Gutmann and Dennis Thompson, "Deliberative Democracy Beyond Process," 31-53 [B]
- Cass Sunstein, "The Law of Group Polarization," 54-79 [C]
- Iris Marion Young, "Activist Challenges to Deliberative Democracy," 102-20 [D]
- Ian Shapiro, "Optimal deliberation," 121-37 [B]
- Philip Pettit, "Deliberative Democracy, the Discursive Dilemma, and Republican Theory," 138-62 [C]
- David Miller, "Deliberative Democracy and Social Choice," 182-99 [D]

Gutmann, Amy and Thompson, Dennis. "Just Deliberation about Health Care," in Ethical Dimensions of Health Policy, edited by Marion Danis et al (Oxford University Press, 2002), 77-94. [C] Note: They are discussing a case [PUREPAP Rescreening] that I analyzed in an essay. They use my arguments and analysis but fail to reference me.....BAD FORM!!!!

Gutmann, Amy and Thompson, Dennis. Democracy and Disagreement (Harvard University Press, 1996), 1-51. [B]

Macedo, Stephen (ed.). Deliberative Politics: Essays on Democracy and Disagreement (Oxford University Press, 1999). I commend to your reading the following essays from that volume:

Frederick Schauer, "Talking as a Decision Procedure," 17-27

William Simon, "Three Limitations of Deliberative Democracy: Identity Politics, Bad Faith, and Indeterminacy," 49-57

Cass Sunstein, "Agreement Without Theory," 123-150.

Norman Daniels, "Enabling Democratic Deliberation: How Managed Care Organizations Ought to Make Decisions about Coverage for the New Technologies," 198-210.

Jane Mansbridge, "Everyday Talk in the Deliberative System," 211-41

Bohman, James. Public Deliberation: Pluralism, Complexity, and Democracy (MIT Press, 1-69. [D]

Bohman, James and Rehg, William (eds). Deliberative Democracy: Essays on Reason and Politics (MIT Press, 1997). All the essays in this volume are well worth reading, but here are some to which I would especially call your attention:

Jon Elster, "The Market and the Forum: Three Varieties of Political Theory," 3-34.

Joshua Cohen, "Deliberation and Democratic Legitimacy," 67-92 [B]

David Estlund, "Beyond Fairness and Deliberation: The Epistemic Dimension of Democratic Authority," 173-204. Estlund has a book-length extension of this argument in his new book Democratic Authority: A Philosophic Framework (Princeton University Press, 2008).

Gerald Gaus, "Reason, Justification, and Consensus: Why Democracy Can't Have it All," 205-42. [C]

Thomas Christiano, "The Significance of Public Deliberation," 243-78.  
James Bohman, "Deliberative Democracy and Effective Social Freedom:  
Capabilities, Resources, and Opportunities," 321-48.  
Joshua Cohen, "Procedure and Substance in Deliberative Democracy," 407-38 [D]  
**Cohen is one of the early articulators of the theory behind deliberative  
democracy.**

Stokes, Susan. "Pathologies of Deliberation," in Deliberative Democracy, edited by  
Jon Elster (Cambridge University Press, 1998), 123-39.

Cohen, Joshua. "Moral Pluralism and Political Consensus,"  
in The Idea of Democracy, edited by David Copp, Jean Hampton, and John  
Roemer (Cambridge University Press, 1995), 270-91. [B]

Rawls, John. "The Domain of the Political and Overlapping  
Consensus," in The Idea of Democracy, edited by David  
Copp, Jean Hampton, and John Roemer (Cambridge Press,  
1993), 245-69.

Goold, Susan. "Allocating Health Care: Cost-Utility Analysis, Informed  
Democratic Decisionmaking, or the Veil of Ignorance," Journal of  
Health Politics, Policy, and Law, 21 (Spring, 1996), 69-98.

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(Georgetown University Press, 1995), 198-207.

Fishkin, James. The Dialogue of Justice: Toward a Self-Reflective  
Society (Yale University Press, 1992).

Fishkin, James. Democracy and Deliberation (Yale University Press,  
1991).

Sunstein, Cass. Legal Reasoning and Political Conflict (Oxford University  
Press, 1996). The concept that I will want to pull out of Sunstein's work  
is that of "incompletely theorized agreement." I will ask you to compare  
the utility of that notion to the expectation of Daniels and Sabin that a fair  
rationing process requires the explicit "giving of reasons." Also, how is  
Sunstein's notion related to Rawls' notion of an "overlapping consensus"?

Wall, Steven. "Public Justification and the Transparency Argument," *Philosophical  
Quarterly* 46 (1996) 501-07.

Chambers, Simone. "Behind closed Doors: Publicity, Secrecy, and the Quality  
of Deliberation," *Journal of Political Philosophy* 12 (2004), 389-410.

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## **VI. JUST HEALTH CARE RATIONING: A RATIONAL DEMOCRATIC DELIBERATIVE APPROACH, PART II (Liberalism and Public Reason)**

One of the important theoretical sub-areas in the philosophic debates about rational democratic deliberation in a liberal society pertains to Rawls' notion of public reason. Rawls brings together his own conception of public reason in his book Political Liberalism and in some subsequent articles. The basic problem we will need to consider is this: The focus of our discussion is *rational* democratic deliberation. We are not talking about casual political discussions. These are rationally-ruled discussions; and I take it that the concept of public reason is intended to reflect that. However, political scientists will typically describe our society as being *liberal and pluralistic*. That raises this basic question: **Is it possible to construct a form of public reason that is compatible with a political society that is liberal and pluralistic?** Rawls will want to give an affirmative answer to this question. He will, in effect, say that public reason can be respectful of our pluralistic political heritage by avoiding internal commitment to any comprehensive philosophic or religious doctrines. Rawls will sometimes say that public reason must be sceptical about such comprehensive doctrines. But then that raises a subsequent difficult question: **Can public reason of this somewhat attenuated form be robust enough to generate a substantive enough and complex enough conception of health care justice that can effectively address the moral problems that need to be addressed?** [Rawls obviously believes that public reason can generate a robust enough conception of social justice (though critics will disagree with Rawls' self-assessment in this matter). Apart from that, as we will have noted earlier, there are features and facts about our health care system that make it more problematic from the perspective of political liberalism, as we discuss below.]

The other large issue we raise is what I earlier referred to as the “liberalism problem.” There is a debate among political philosophers as to whether or not political liberalism of a Rawlsian or Dworkinian variety is itself a comprehensive doctrine that unjustifiably infects the concept of public reason that Rawls wishes to defend. If that is the case, that would undercut the political legitimacy of such a notion of public reason since, in effect, others in our society who were not deeply committed to this version of political liberalism would be forced to live with laws and policies that were contrary to their deepest political values. But there is another liberalism problem, which will require significant attention from us. It is: **How can we reconcile the demands of health care justice with respect for the deep value commitments (conflicting commitments) of various religious groups in our society, or political groups with deep distinctive values, such as advocates for various groups of persons with disabilities?** The quick examples would be these: If we can come to agreement that all in our society ought to be assured access to a fairly thick package of health benefits, then should physician-assisted suicide be a covered benefit? Or any of a broad variety of new reproductive technologies, some of which will require the destruction of embryos? Or pre-implantation genetic diagnosis of eight-cell embryos for purposes of discarding embryos at risk for a serious genetic disorder? Or germline genetic engineering of eight-cell embryos for either curative or enhancement purposes? Or using animals as factories to grow large quantities of genetically engineered drugs for human use? Or the use of 100-cell human embryos as generators of embryonic stem cells that we would use for the regeneration of nerve or organ tissue severely damaged by disease? Or Viagra or Cialis for

problems related to impotence?

Finally, there is this question: **Where does wide reflective equilibrium, as a moral/philosophic methodology, fit in when it comes to articulating just health care policies and just health care practices?** It would seem that any sort of philosophic methodology is just not compatible with the need for compromise when there are conflicting moral and political values at stake. It would also seem that there is something incompatible between a reliance upon democratic mechanisms to address some range of rationing issues and appeal to epistemic criteria (such as those implicit in wide reflective equilibrium) to judge the justness of the outcomes of a democratic deliberative process.

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## **VII. JUSTICE, HEALTH CARE, AND THE GOOD DOCTOR: PATIENT ADVOCATE OR PRUDENT PROTECTOR OF SOCIETAL RESOURCES?**

The focus of our discussion will be the inescapable role of the physician in any system of health care rationing, specifically, the problem of justice for the physician in such circumstances. The basic problem is that physicians are supposed to be uncompromised advocates of the best medical interests of each of their patients. At the same time physicians must take responsibility for determining who gets what kind of medical care when there are limits on the medical care that he/she may legitimately provide. That is, the framework of justice is one that physicians cannot simply ignore. How then are physicians supposed to reconcile these competing responsibilities? One answer, advocated by Veatch, is that all rationing decisions should be made in categorical terms at some policy or administrative level. Physicians would then have their hands tied. They simply would not be permitted to act against such policies on behalf of their patients, so they could justifiably claim that they are being as loyal as possible, given the constraints that have been imposed upon them from above. When we speak of a "policy or administrative level decision" we have in mind either Medicare/ Medicaid policy as represented by something like DRGs [budgets for the care of individual patients with specific medical diagnoses], or policy decisions that might be made within a managed care plan.

But it does not seem this is an entirely acceptable position to adopt, either from a moral or a clinical perspective. Categories are always crude devices for effecting rationing decisions; and there is typically great variability in the medical circumstances of individual patients within the same medical/disease category. A morally sensitive physician could hardly acquiesce to such administrative rationing positions, if he/ she believed a given patient was an outlier relative to a certain rationing policy. If an appeals process is introduced, then a physician once again is put in the position of having to decide whether an appeal is warranted in the case of a specific patient, which then just brings us back to our original dilemma: How could a conscientious physician fail to make an appeal for all but the most moribund of his patients?

There is another response made to Veatch by Morreim, namely, that no administrative rationing mechanism can just work by itself without the active involvement of physicians in implementing that mechanism. How then can physicians reconcile for themselves in their clinical behavior these competing moral frameworks. We shall want to argue that such a reconciliation is possible, even if only in somewhat idealized circumstances. But even if that argument is successful, the follow-up question will still be troubling, namely, are physicians morally obligated to inform their patients of the fact that they are being denied some sort of medical care that might have been beneficial for them, but is in fact being denied them because the likely benefits are too small relative to the actual costs of providing that treatment. Or is it sufficient, if, for example, patients belong to an HMO, that such decisions are simply made by physicians without explicitly informing patients of options being denied them on the grounds that patients were duly informed, when they joined the HMO, that they were buying into a system of "constructive rationing," that this was high quality health care they were getting at a reduced price because in at least a state of wellness they had made the judgment that such a trade-off had made sense. That is, they have already agreed to the making of such rationing decisions by their

caregivers. Consequently, there is no need to get explicit consent from patients each time a patient is denied a potentially beneficial, though only marginally so, medical service.

Finally, the context for this discussion is primarily managed care plans (though managed care plans are very often acting in accord with the wishes of large employers who have actually demanded a range of restrictions and limitations in their specific health plan), though there have always been incentives shaping physician behavior that were not always congruent the best interests of patients. We cannot consider all of these issues. We will really not have time to address the question of whether the rapidly spreading profit motive in health care threatens to undermine even further the fairness of the system. We should not ignore the role of competition in health care today as more of a market-dominated system. To what extent does competition among managed care plans threaten to make more unjust such plans? But we will pass over that issue as well rather quickly. Instead, we will give some attention to the way in which various cost control schemes used in managed care plans potentially threaten both fair treatment of patients by physicians and the best interests of patients. Two such mechanisms are known as 'capitation' and 'withholds. These are described by analysts as 'incentive mechanisms.' The alternative is to rely upon 'rules' to control costs by controlling physician behavior. 'Rules' cover clinical guidelines, practice protocols, utilization review, formal rationing protocols, drug formularies, etc. Rules are typically seen as doing a better job of protecting 'just allocations,' but incentives are seen as being better for giving physicians the sort of clinical flexibility needed to be responsive to individual patient circumstances.

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## VIII. JUST CARING: IS AGE-BASED HEALTH CARE RATIONING MORALLY DEFENSIBLE?

As we noted in class already, there are special problems of justice that arise in connection with the elderly. These problems arise because the elderly consume a disproportionate share of health resources in our society, roughly three times as much in the way of health resources as the non-elderly. From a utilitarian perspective, this does not seem to be a wise use of society's limited resources. This perspective may not seem to be especially attractive, and it may seem to warrant discriminatory treatment of the elderly. Do we solve our problem if we say that health care ought to be distributed in accord with need: greater need means greater entitlement? This perspective has greater initial moral attractiveness, but it does seem to have some practical drawbacks (as well as moral drawbacks). For there is the risk that the elderly could hijack the health care budget because of their virtually limitless health needs (which seem to expand with expanding medical technology); and this would seem to threaten the fair treatment of non-elderly individuals in our society who have significant health needs. **So, how can we fairly distribute health resources among the elderly, and between the elderly and the non-elderly, such that we respect their autonomy and accord equal respect to their basic moral rights?**

Would we act unjustly if we were to reduce the access of the elderly to some of the more expensive forms of health care available, such as they have done in Great Britain? If so, should we use a simple age criterion, such as age 70 or 75? Or should we add to the age-criterion some present-or-future- quality-of-life criterion as well, the point being that those with relatively low quality of life (mental status/ functional abilities), or those whose quality of life would only be worse as a result of medical treatment, would have less of a claim on health care resources? Are we capable of making such quality of life judgment in ways that are reasonable, objective, above moral criticism? Or do we risk the charge of age discrimination? And to what extent do we allow individual elderly persons (or their surrogates) to have a say with regard to such quality of life judgments? Or should we add a "probability of success" criterion to our judgments? That is, where the likelihood of a successful medical intervention is small, say, less than 10%, and if success means only a marginal gain in life expectancy or quality of life, would we be morally justified in denying access to that kind of medical care? This would be close to some sort of "costworthy" criterion such as Menzel would advocate. Think about these issues in relation to several of the paradigm cases I introduced the very first night of class, such as the Wanglie case. *Or think about a case such as this.....an 85-year old in excellent health due to an excellent genetic endowment, except for a life threatening cardiac problem.....quite manageable with the help of a totally implantable artificial heart for \$300,000. Does that individual have a just claim to that resource? Is a just and caring society morally obligated to sustain his life because his genetic endowment will yield for him a predicted "natural life expectancy" of 95 years? Could he justifiably claim, if denied the artificial heart, that ten years of his life were taken from him unjustly by society? Why or why not?*

Is there further need for reform of the Medicare program in order to make sure that the Medicare program does not go bankrupt, and in order to make sure that Medicare is only paying

for costworthy care, or only paying for care that meets the real health needs of the elderly? If reforms are needed, what do you think those reforms ought to be in order to bring about a more just Medicare program? Should we, for example, continue to increase the Medicare premium and co-pay requirements so that the elderly themselves become rationing agents for their own care? Should we abandon the DRG prospective payment mechanism in Medicare? If so, what sort of cost containment devices ought to replace that mechanism? Also, what should we be doing, if anything, to better meet the long term care needs of the elderly? Should the elderly be willing to trade-off access to expensive life-prolonging acute care for long term care? Should a prescription drug benefit have been added to the Medicare program at a likely cost of \$830 billion over a ten-year period of time [2007-2016] [Bush plan], out of projected total drug expenditures for the elderly of \$2.1 Trillion for that ten-year period. If you reject the Bush plan, what would you see as a more just alternative that did not bust the federal budget? Note: Current Medicare budget [2007] is about \$430 billion. These last questions are important because they speak to real matters of public policy, and introduce the problem of justice in non-ideal circumstances. This is a problem I address in my article on DRGs, and I will be curious as to whether you see my approach as being philosophically useful and defensible. NOTE: I know that it will be possible, for reasons of time, to delve into great depth on the policy issues raised in this course. For virtually every seminar meeting there are very salient policy issues we could discuss. Most of the time I will ask you to be satisfied with a cursory identification of the relevant issues. But we ought to do at least one in-depth bit of policy analysis, just so you see what it needs to look like, what you need to be prepared to think about as a philosopher in some part of the policy arena.

Yet another set of issues of justice that we need to address pertains to justice within intimate relations. The starting point for this problem is the high level of functional disability among the elderly over the age of 85. About 25% of the elderly above age 85 are unable to care for themselves. Most of these infirm elderly are cared for by family members, typically daughters. The issue we are concerned with here is whether this involves obligations of justice or moral considerations related to beneficence. While we might think of this as a matter of "personal morality" my intent is to focus on the implications for social morality and social policy. More specifically, the home care that is provided now by family members is a "free good" so far as the government is concerned (or other third-party payers of health care). Yet it can be argued that it is women for the most part who are exploited in these circumstances because they must give up substantial personal time and career opportunities to provide this care. Is this something that a just and caring society may passively tolerate? The alternative, of course, is that such care could be paid for. If we did that, however, the result would be either a major exacerbation of the problem of escalating health costs, or else the need to "balance the budget" by not purchasing other kinds of health services that would be judged to be of lower priority. We might, for example, routinely deny an 80-year old advanced Alzheimer's patient with failing kidneys dialysis (cost=\$100,000 per year), which would mean they would die from uremic poisoning rather than living a couple more years in a demented state.

The other issue of health care justice within families pertains to resource allocation with respect to terminally ill, competent or incompetent elderly patients. There may be a potentially life-saving medical intervention that offers only a 10% chance of such success, that costs more

than \$100,000, that is judged "experimental" by insurance companies (and the government), and hence, that will have to be paid for from private funds. May a surrogate decisionmaker refuse that therapy for a now incompetent patient in order to avoid leaving that patient's (future) widow in bankruptcy? Or in order to protect the estate for adult children who are struggling financially? And if the patient is competent and desperately wants that resource, even if it means leaving his widow bankrupt, does he have a just claim to those familial resources for that purpose? Or do we want to argue that considerations of justice are irrelevant within the family, that there are other moral norms that must be dispositive in such circumstances? If so, then we need to ask whether there are any "spillover effects" so far as justice is concerned for society in such situations? That is, if family members refuse to accept the financial and emotional and personal burdens of caring for the dying and seriously chronically ill, then does our moral norm of "just caring" require that society at large assume those burdens?

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## **IX. JUST CARING: JUDGING FAIRLY THE HEALTH CARE NEEDS OF THE TERMINALLY ILL, THE CHRONICALLY ILL, AND THE CATASTROPHICALLY ILL**

This is something of a grab bag class in that there are many categories of patients we need to consider in order to determine whether or not legitimate discriminations may be made among those who may or may not be entitled to a certain level of health care. If there is one factor that binds these diverse categories together, it is the fact that all these types of patients represent high cost users of health services in our society. The relevant statistic is that the 5% of patients in the US who are sickest in any given year consume 54% of health resources in a year, which would be about \$1.2 trillion in 2007. What follows from that? **Should cost-effectiveness be the predominant criterion we use for determining how we prioritize all the sorts of patients who are the focus of this class session? [Note what Ubel has to say about this question.] To what extent, if any, should personal responsibility for having costly health needs be used to determine whether or not those needs will be met? Or is the most morally apt consideration with regard to these categories of patients that they are clearly the “worst off,” and therefore deserve the highest priority so far as access to health care is concerned? [Would this be a proper application/ interpretation of a Rawlsian conception of justice?]**

The patients who should first get our attention are those who are terminally ill. A statistic you will come across in your readings is that 28% of all Medicare dollars are spent on the 6% of Medicare patients in their last year of life. The implication is that this represents a wasteful use of health resources, and hence, a way of using health resources that is morally optional, rather than something being required by justice. But among the practical difficulties we will run into is that of whether or not an accurate judgment can be made at the bedside of who is terminally ill. **At the philosophic level or conceptual level, the issue will be that of deciding to whom the label "terminally ill" is properly affixed. At the moral level the issue is whether the terminally ill have just as much a moral right to whatever health services might prolong their life for what they judge a significant enough period of time as the non-terminally ill. That is, do we treat the terminally ill unjustly if we deny them the health intervention that costs \$100,000 and that will give them an additional month of life? Or six months of life? Or an extra year of life?**

One of the central problems we will need to address in the course is the “last chance therapy” problem. We will take it up explicitly in our next seminar meeting, but this is a good place to introduce the problem. We asked in the prior paragraph who the terminally ill are. One common response is to say that individuals who have a predicted life expectancy of six months or less are “terminally ill” in the strict sense of the term. What “last chance therapies” represent is an opportunity for rescue. **Does everyone have a moral right (just claim) to such rescue (or multiple rescues), no matter what the cost, no matter how small the gain in length of life, no matter what the chance that the rescue attempt will be successful, no matter what is sacrificed in terms of meeting the health needs of others, no matter what the age, no matter what the quality of life, etc.? To put this more concretely, should it be the case (as a matter of health care justice) that an AIDS patient at age 38 who has failed protease inhibitors should have ONLY an EQUAL RIGHT to expensive life-prolonging fusion inhibitor**

**therapy relative to an 85-yr old with mild dementia who needs an artificial heart at \$300,000 for two extra years of life? Or should that AIDS patient have a stronger moral claim? And, if so, what would be the moral basis for that stronger claim?**

One of the more difficult issues we need to consider here are children who are faced with a terminal illness. As with adults, the cases we need to consider are enormously heterogeneous. We can ask: **Do they have stronger just claims to expensive, life-prolonging health resources than adults with comparable medical problems and comparable prospects of success/ failure just by virtue of the fact that they are so young, that they have had little opportunity to live a life? How should we think about the just claims to health resources for anencephalics [Baby K problem]? For children with necrotic small bowel syndrome [costs of \$300,000+ per year to sustain their lives, maybe for 4-6 years]? For children born with Trisomy 18? Trisomy 13? With a range of serious genetic disorders? With early childhood cancers that are usually fatal? Children who are HIV+ at birth? [Note: Most of the problems of justice we discuss are problems of social justice. But there may be problems of justice within a family that can have consequences for various family members that are a problem of justice as well, but not readily addressed at the social level. Some of these very ill children may have their health care paid for by public or private programs of various sorts, but the burden on parents (and other children) may still be largely unrelieved. In such circumstances, may parents elect to forego further life-sustaining care for these chronically ill children in order to more fairly meet the needs of other family members? ]**

A second category of patients we need to discuss are patients in a persistent vegetative state or patients in advanced states of dementia. How much do we as a society owe such patients in the way of expensive life-sustaining health care as a matter of justice as opposed to charity? You need not think of any especially exotic or invasive medical procedures in this connection. Most often we are simply talking about feeding tubes and antibiotics and basic nursing care. But individuals can be kept alive for many years under such circumstances with minimal capacity to appreciate the life they have. The most recent example that garnered all manner of national political attention was the case of Terri Schiavo. An expanded version of our question might include the profoundly retarded. Just to put some numbers to this discussion, it is estimated that there are 10-25,000 individuals in PVS right now, and the annual cost of their care is about \$2 billion. There are about one million individuals in nursing homes today at a cost of about \$60,000 per person per year. {NOTE: Those are just the nursing home costs. Any additional medical care to treat diabetes or congestive heart failure or failing kidneys etc. represents high extra costs.} It is predicted that by the year 2025, when much of the baby boom generation will have aged out, there will be four million individuals needing nursing home care.

The third large category is that of the catastrophically ill, or what Wikler and Daniels refer to as "bottomless pits". In itself this is really a very heterogeneous group. It includes, for example, individuals who have suffered very severe head injuries that have left them mostly paralyzed, who now have enormous rehabilitative needs, plus a constant stream of other medical problems that repeatedly arise and need attention. The question we need to raise is whether individuals ever reach "the limit" beyond which a society could deny further health care to these

unfortunate individuals, that is, health care that is paid for from social resources. There are lots of serious (but not immediately fatal) chronic diseases that would put individuals in this category, such as renal disease with the need for dialysis at a cost of \$53K+ per year, not to mention side effect problems requiring additional medical care and hospitalization. AIDS might be another example we could mention. Dr. Fauci predicted in 1993 that by the end of this century AIDS will just be a chronic disorder, not fatal. What he did not predict is the cost of keeping someone alive with a broad assortment of very expensive drugs needed to respond to one or another health crisis precipitated by the AIDS virus. Right now each of the individual drugs AIDS patients need is very expensive. What becomes problematic is the fact that the number of such afflicted individuals in the future is likely to be very large (over one million) and grow each year. To what extent should such numbers "count", morally speaking? Again, to give a specific example, protease inhibitors are the drugs that may in fact verify Dr. Fauci's predictions. But the cost of those drugs is roughly \$16-20,000 per year. Those drugs have had truly dramatic effects in suppressing the AIDS virus, often to undetectable levels. But no one knows how long that effect might last; the virus may be able to mutate after some period of time and overcome the limitations imposed by various protease inhibitors. [In point of fact, we have learned since 1997 that the virus does mutate around these drugs, eventually defeating all the protease inhibitors. There is a lot of variation from individual to individual for reasons not well understood. In 2003 we saw the introduction of fusion inhibitors, which will raise the cost of prolonging these lives to \$35,000 per patient per year. And often these drugs have costly medical side effects not reflected in that \$35K figure. Yet other drugs are in the pipeline for the time when the fusion inhibitors will be defeated as well. You should also know this same argument has recently been made with regard to cancer. That is, few expect to defeat a cancer, especially if it has metastasized. So now the clinical hope is that cancer in its advanced stages can be "reduced" to a long term chronic illness with drugs that will in various ways prevent cancer cells from multiplying by defeating in various ways their capacity to access healthy cells.] In the meantime, given the cost and uncertainty, what is a just and caring society morally obligated to do by way of assuring access to these drugs? How high a priority ought access to these drugs have, relative to all the other unmet health needs in our society? Relative to all other chronic health care needs in our society? I will also introduce comparable issues related to hemophiliacs, where the cost per life-year saved might be \$100,000 and where some interventions can cost up to \$5 million for one person with only a 30% prior probability of success. Roughly 15% of hemophiliacs will not be able to tolerate Factor VIII; they are the candidates for that intervention that can cost \$5 million. Today, this intervention is considered for children around age five. This lowers the cost to around \$2 million per child.

Finally, there are those patients that some analysts call RHSDs, or Repeated Hospitalization for the Same Disease. They may be responsible for 17% of our total annual health expenditures [\$390 billion in 2007]. This category includes individuals who are drug abusers, alcoholics, smokers with COPD or other lung problems, diabetics, very obese individuals, individuals with heart disease who fail to follow their diet and medication regimens, etc. **What is distinctive about this group, morally speaking, is that at some level we would judge that they are repeatedly responsible for their current health needs (hospitalization), and this seems to impose a very significant burden on the rest of the health care system, a burden which some would call unfair. Is that a correct moral judgment? Do we have some sort of rule or other**

**relevant moral considerations that would allow us to set a limit to the amount of health care that had to be provided to such individuals as a matter of justice?**

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**X. HEALTH CARE, JUSTICE, ORGAN TRANSPLANTS AND OTHER EXPENSIVE LIFE-SAVING, LIFE-PROLONGING MEDICAL TECHNOLOGIES: THE CHALLENGES OF 'LAST CHANCE' THERAPIES**

William Schwartz has argued that the largest single factor responsible for escalating health care costs is the expansion of medical technology. The more technology we have, the more we can do by way of responding to medical problems of individuals. The problem is that relatively little of this technology is curative in any definitive sense. Most of it is what is referred to as "half-way" technology, which will prolong life without curing the underlying medical problem, such as renal dialysis, or bypass surgery, or much cancer chemotherapy, etc. Moreover, much of this technology adds to the total expense of health care because of side effects that are generated and that themselves require further medical interventions. Needless to say, much of this technology seems to do a significant amount of good, at least in the eyes of those who receive it.

Among some of the larger questions we need to address are the following: On the assumption that we cannot fund in the future for everyone all that might become available in the way of life-sustaining medical technology, what criteria should be used for determining which technologies will be introduced into the health care system and which will not? To focus our attention, you might consider the case of the totally implantable artificial heart. Unlike natural hearts (only a limited number of which are available for transplant purposes) there is an unlimited number of artificial hearts that could be produced. Should we just ban the development of such a device? Should we limit the production of the device to a certain number each year, such as 10,000? Would that be unjust in any sense, given that the potential need for such devices could be as high as 350,000 per year? [Note: That figure of 350,000 assumes restriction of access to that device to those with a predicted gain in life expectancy of five years. If we find that limitation unacceptable, then the numbers and cost balloon rapidly. At the 350,000 level the TIAH would add \$100 billion per year to the total cost of health care in the US.] If we were to restrict production of TIAHs to some figure less than 100,000, then what sort of morally justifiable criteria could be used to determine which specific individuals would have access to those hearts? Each of those surgeries, by the way, would cost \$300K (\$2007). Another dimension you have to bear in mind as you think about this issue is that of the financing of health care in America. If you ask this question in the context of our presently highly fragmented system for financing care you get one answer. If you think of it as a question in the context of a single system for national health insurance, then you get a very different answer. Keep in mind that the artificial heart only represents a response to heart disease, a partial response at that. Does anyone who suffers from cancer, COPD, liver failure, stroke, etc. have any justified moral complaint if there are comparable technologies for their medical problems which have not been publicly funded? [NOTE: An artificial liver is in development right now, somewhat comparable to the artificial kidney. In this same category would be lung reduction surgery for COPD, or the left ventricular assist device for congestive heart failure.] Something to keep in mind is the nationally funded dialysis program that was put in place in 1972 under the Medicare program. That program pays for dialysis or kidney transplants for ALL who have kidney failure. It is a sort of national health insurance program for failed kidneys. Is such a program unfair to those with other failing organs? That program currently (2007) supports 410,000 individuals in the US at a cost of about \$23

billion per year. Projections are for that figure to rise to 600,000 patients by the end of the decade. You should know that kidney failure is most often associated with diabetes and heart disease, which means that the cost of dialysis represents only a fraction of the total annual health care costs for the vast majority of this class of patients.

In this class we will examine justice and allocation issues at both the micro and macro levels. **One macro question we can discuss (which I address in my essay) is whether we [citizens in a just and caring society] are open to moral criticism if we fail to maximize by whatever morally legitimate means the supply of transplantable organs.** That takes us off in the direction of “required request” policies, “presumed consent” policies, xenotransplants [pig organs], paying people to donate organs as an incentive to relatives, liberalizing the “dead donor” rule, etc. **At the micro-level, when we have some absolutely scarce life-saving good, whether a transplantable organ or an ICU bed, what criteria are most just in determining who ought to have access to such a good? One large question would be: To what extent should future quality of life play a major role in shaping such allocation decisions? Also, in the field of organ transplants, there is the issue of re-transplantation: If an organ, such as a liver, fails too soon after transplantation (less than a year) should that unfortunate individual be moved to the top of the transplant list for a second organ?**

But there is a broader issue we will need to address, which is much more complicated than the organ transplant problem. That is the “last chance therapy” problem. The organ transplant problem is in some respects morally manageable because the bottom line is that there are absolute limits (or near limits) on the availability of these natural organs. When, however, we create artificial substitutes for natural organs, there is no natural limit on their availability. This is why there are currently about 410,000 individuals on dialysis. As we discussed earlier in the course, dialysis creates enormous moral pressure because it does literally rescue individuals from imminent death. It was believed in 1972 that this technology was unique, and therefore, deserved social investment to prevent these otherwise premature deaths. But we know today that the technology is not unique; there are dozens of medical interventions that can be described as “last chance therapies,” including drugs such as Xigris for septic shock, which can have costs in excess of \$500K per life saved. *NOTE: Just so you understand what that \$500 K figure means, the drug itself costs about \$7,000 per dose. That \$500K figure means that administering the drug rarely makes a difference in outcome. That is, the patient was either doomed to die or destined to survive whether or not they received the drug. Only in a small percentage of cases is the outcome altered.*

Further, there are literally millions of individuals in any given year who can be beneficiaries of one or another of these last chance therapies..... often several times at very great cost each time. Because life itself is at stake we are tempted to think we are morally obligated to make available each and every one of these last chance therapies, no matter what the cost, no matter what the probability of success, no matter what the quality of life, no matter what other health care interventions are given up for others, no matter what the age of those “rescued,” no matter how brief the length of life that is saved. But, as I argued earlier, this is not a reasonable or morally defensible conclusion to draw. **So then our question is: What are the morally**

**relevant considerations that can yield just rationing decisions with respect to last chance therapies?**

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## XI. JUST CARING: THE MORAL CHALLENGE OF FAIR ACCESS TO EMERGING GENETIC AND REPRODUCTIVE TECHNOLOGIES

While it may seem that the debates on health reform are already complex enough, the fact is that the emerging field of genetic technology is going to make them even more complex. There are issues related to the development and dissemination of somatic cell gene therapy, which we will need to discuss as well, especially since these therapies are beginning to show some promise. These therapies are novel, but from a moral point of view, they do not seem to raise any distinctive problems of health care justice. However, germline genetic engineering does raise what seem to be some unique moral challenges. Here we have in mind the genetic alteration of eight-cell embryos in vitro, either the removal of genes associated with serious genetic disorders (CF, HD, AD, Tay-Sachs, Fragile X, etc) and their replacement by normal copies of that gene, or else the enhancement of an individual genome by replacing normal genes with superior versions of those genes (connected with parentally or socially desirable traits). [I introduced the discussion of this issue in a paper published in Lappe/Murphy, Justice and the Human Genome project (1994), and there have been a couple excellent articles by Buchanan since that address these issues.] Rawls sees the problem of justice as starting with the acceptance of our natural genetic endowment, then going from there, because when he wrote A Theory of Justice germline genetic engineering was nothing more than science fiction. But it is very nearly scientific reality today, so there are justice issues. **If we have the capacity to do germline genetic engineering (and it is likely to cost \$50,000 per engineered embryo), then is access to such technology a matter of social justice? If so, what precise considerations of justice might shape the particular allocation policy we develop? How high a priority in the total scheme of health needs should this technology have? Would we provide access only to negative germline engineering at social expense? Would a just and liberal society, anxious to prevent the emergence of a genetic superior class be justified, in preventing the dissemination of germline engineering aimed at embryonic enhancement? [NOTE: The focus of this seminar session is on genetics and reproductive decisionmaking. So, much of our discussion of “enhancement” issues in medicine will have that focus. However, “enhancement” can be achieved in many different non-genetic ways in medicine. This is really what Viagra and Cialis are about. Identifying what counts as “enhancement” is far from obvious in many cases. Impotence is a real and serious medical problem for a man who is 30 or 40. Is it equally thought of as a genuine medical problem at age 70 or 80? Prozac is effective in treating serious depression for many. But Prozac can also be used to treat “shyness.” Is this another form of enhancement? And how should we think about this from the perspective of health care justice? If we had a national health insurance program, would we be morally obligated to cover Prozac as a treatment for shyness? [Note: A nice collection of essays around these “enhancement questions” is Enhancing Human Traits: Ethical and Social Implications, edited by Erik Parens (Georgetown University Press, 1998).]**

Note: The point of some of these questions around reproduction is to suggest that other values besides justice must come into play when it comes to thinking through some of these issues as social policy issues. Certainly one large value will be the value of procreative liberty. **We might all agree in a vague way that society ought to be respectful of procreative liberty, i.e.,**

**ought to not interfere with the procreative decisions made privately by individuals. Does such respect also include financial support for exercising such liberty so that it can in fact be “effective liberty”? Apart from the liberty issue there is the issue of “genetic responsibility,” either as a private moral obligation or as a social obligation. Here, there is first the conceptual/ normative issue: How can we distinguish “genetically responsible” from “genetically irresponsible” decisions? Ought a society be more “genetically responsible” by providing resources to parents who wish to avail themselves of alternate reproductive technologies that will allow them to avoid the conception/ gestation of a child with serious genetic disorders? And, can a ‘liberal’ society have social policies aimed at supporting/ incentivizing “more responsible” reproductive decisions?**

Apart from these more radical forms of genetic therapy/ genetic enhancement there are today numerous issues related to fair access to genetic testing. There are now more than 1000 genetic tests that are commercially available that can be used for a variety of purposes, including prenatal genetic testing, diagnostic genetic testing, asymptomatic genetic testing, pre-marital genetic testing, genetic testing directed toward “susceptibility” genes, etc. These tests are at least somewhat expensive and often yield very mixed results. The average test may have costs of about \$300, but tests that involve identifying as many as several hundred mutations of a single gene, as in the case of the BRCA1 gene, associated with breast cancer, can easily cost \$2400 or more. Is a just and caring society morally obligated to pay for all these tests? Some of these tests? How could we determine how much priority (from a justice perspective) these tests ought to have relative to one another, or relative to other sorts of medical tests? Do employers or insurers have a right to know the results of these tests (in order to protect what insurers refer to as “actuarial fairness”)?

From the perspective of health care justice, how should we think about the problem of infertility? Is a just and caring society morally obligated, as a matter of justice, to provide some level of access to alternative procreative options for those who cannot reasonably hope to conceive children of their own in any other way? Or is access to such services justly left entirely to market mechanisms and individual ability to pay? Going back to our genetic issues, if a couple knows they are at risk for having a child with a serious genetic disorder [25% chance of cystic fibrosis], is a just and caring society morally obligated to provide them with financial support [100%; 80%; 50%] for accessing some alternate reproductive technology that would permit them to avoid having an affected child? In vitro fertilization might cost \$15,000 to achieve a pregnancy; pre-implantation genetic diagnosis will cost about \$40,000. **Looming over this entire discussion is what we introduced earlier as the “liberalism” problem. Virtually all of the genetic and reproductive technologies we will discuss have been the focus of intense social/ ethical controversy. Is it therefore morally objectionable that we (society through government policy) should force members of society who have objections to these technologies to pay taxes to support various public programs that could pay for these interventions? Why or why not?**

We do not ordinarily think of Medicare in connection with issues of genetics and reproductive decision making. However, this is where the issue of cloning is being resurrected, as

part of the emerging world of regenerative medicine through embryonic stem cell research. This area of medicine will prove most useful to a largely older population that will need to repair diseased brain tissue or heart tissue or pancreatic tissue or nerve tissue with embryonic stem cells.

These cells will have to come from individuals themselves in the form of embryonic clones of themselves, grown to the 100-200 cell stage, from which these embryonic stem cells would be harvested and manipulated and mass produced for a specific medical purpose. **Is a just and caring and liberal society morally obligated to support through Medicare access to these new technologies in the field of regenerative medicine, despite the moral and political controversy that surrounds them?**

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## **XII. JUST CARING: SETTING HEALTH CARE PRIORITIES REGARDING THE HEALTH CARE NEEDS OF PERSONS WITH MENTAL AND PHYSICAL DISABILITIES**

There are sometimes very expansive definitions of who “the disabled” are, such that all the cases discussed in the prior two chapters would have to be discussed again in this chapter. I want to circumscribe that category a bit more. I may not be able to do that in a perfectly neat way, but some rough boundaries may be possible. I have in mind individuals who have suffered various sorts of catastrophic injuries, often as a result of accidents, leaving them as paraplegics or quadriplegics or as vent-dependent quadriplegics, or perhaps as a result of a stroke or head injury or birth injury. With advances in rehabilitation medicine there are virtually unlimited possibilities for restoring various degrees of functioning. **Our key questions in this chapter are: How do we determine what the limits are for such patients in access to rehabilitative medicine? Do they have a just claim to anything and everything that offers any benefit, no matter how costly, in terms of functional restoration? Does rational democratic deliberation offer any resources for addressing an issue such as this? Or are such individuals vulnerable to discrimination by individuals who cannot adequately understand their needs?** We might be tempted to say (to avoid prejudicial societal attitudes) that only persons with disabilities should be allowed to make rationing decisions for themselves through their own rational democratic deliberative process. But we need to try to imagine what that might look like. There are no generic persons with disabilities behind a veil of ignorance. There are only individuals with very specific disabilities who are very mindful [not impartial] with regard to their specific health needs related to their disabilities. **If their deliberations must occur within the confines of limited hard budgets, then how do they avoid irreconcilable conflicts with respect to how priorities must be set among a broad array of disability needs? [There is no veil of ignorance to assure impartiality.] What sorts of reasons would they offer one another for setting priorities one way rather than another, for this rationing decision rather than rationing decision, etc.? And how should “we” address the rationing problem with respect to persons with disabilities who are incapable of speaking for themselves due to cognitive deficits or incapacities resulting from disease or injury? The broader issue is the question of whether “quality of life” criteria should have moral legitimacy in making just rationing or allocation choices. A recent book that addresses these questions (like I have not given you enough to read already) is Quality of life and Human Difference: Genetic Testing, Health Care, and Disability, edited by David Wasserman, Jerome Bickenbach, and Robert Wachbroit (Cambridge, 2005).**

This is another chapter where there can indeed be argument as to whether or not these issues ought to be given separate treatment. As things are now, mental health issues tend to be treated in a separate category by insurance companies. As with the rest of health care, there are enormous problems related to heterogeneity of mental health needs. [At some level we have to discuss very serious mental disorders, such as manic depression, forms of psychosis, schizophrenia, etc., as well as less serious forms, such as various phobias, anxiety disorders, etc. to “life adjustment problems,” to problems that spill over into the criminal justice system, as when we speak of a variety of “conduct disorders.”] And there are equally heterogeneous approaches to

addressing mental health needs and degrees of effectiveness associated with these approaches. **So we will want to address the question of whether we can establish fair health care priorities among such a broad range of mental health needs, then address the additional question of whether in the final analysis mental health needs must be part of an integrated approach to just health care priority setting, as opposed to remaining as a “carve out” of some sort.** [The outlines of this issue are nicely worked out in The Hastings Center volume (Boyle/Callahan), What Price Mental Health? The Ethics and Politics of Priority Setting.]

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**NOTE: You will notice that a significant number of references included for different seminar meetings are derived from law journals. Many good essays pertinent to social and political philosophy and health care ethics appear in very fine law journals. This is a source that you should be familiar with if your research work is in the areas central to this course. Often these journals devote whole issues to a specific topic related to public policy and some issue in health care ethics. An excellent very recent example is a symposium issue titled "GENES AND DISABILITY: DEFINING HEALTH AND THE GOALS OF MEDICINE." This is from the Florida State University Law Review, 30 (Winter, 2003). Here is a list of authors and essays from that volume:**

**Adrienne Asch, "Disability Equality, and Prenatal Testing: Contradictory or Compatible?"**

**Paul Lombardo, "Taking Eugenics seriously: Three Generations of That???? Are Enough?"**

**Mary Mahowald, Aren't We All Eugenicians? Commentary on Lombardo's 'Taking Eugenics Seriously.'**

**Larry Palmer, "Genetic Health and Eugenics Precedents: A Voice of Caution"**

**Jeffrey Botkin, "Prenatal Diagnosis and the Selection of Children"**

**David Wasserman, "A Choice of Evils in Prenatal Testing."**

**Janet Dolgin, "The Ideological Context of the Disability Rights Critique: Where Modernity and Tradition Meet."**

**John Jacobi, "Genetic Discrimination in a Time of False Hopes."**

**Suzanne Holland, "Selecting Against Difference: Assisted Reproduction, Disability, and Regulation."**

Brock, Dan. "Justice and the ADA: Does Prioritizing and Rationing Health Care Discriminate Against the Disabled?" Social Philosophy and Policy, 12 (Summer, 1995), 159-85.

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### **XIII. JUST CARING: MEETING FAIRLY THE HEALTH CARE NEEDS OF THE POOR/ OREGON AND THE CHALLENGES OF NON-IDEAL JUSTICE (and some further thoughts on Medicare as well)**

Our working assumption is that for the foreseeable future we will continue to have distinct health plans for meeting the health care needs of the poor. That is, we will not have a Canadian style approach to health insurance. If so, how do we know when the health plans we establish for the poor are “just enough”? We are going to focus much of our discussion on the Oregon model. We want to know whether Oregon was justifiably criticized for instituting a program of health care rationing within the Medicaid program. I will argue again (as I did in a paper several years ago) that Oregon’s efforts do meet the relevant tests of non-ideal justice. Further, there are some generalizable lessons regarding just priority setting that can be learned from a close examination of the Oregon experience. We also need to address Menzel’s challenges, namely, that there is something illiberal about giving the poor access to health care instead of giving them cash and allowing them to decide for themselves what their own overall welfare priorities might be.

This is a continuation of the prior class in part; but there is also some shift in emphasis. Specifically, what Oregon developed was an approach to health care priority-setting. The “priority-setting” was to a large extent “for the poor.” But there is a more general issue, which is this: **Is it possible to come up with a fair, feasible, rationally and liberally defensible approach to health care priority-setting? Oregon represents one approach. We want to look critically at that approach and alternatives to it.** [NOTE: As I construct this syllabus, I want to keep things as current as possible. So I am tempted to say that we ought to be discussing the Medicare program in this class as well, and the various efforts and proposals for reform that have been directed toward Medicare (for the elderly). There has been the debate about the prescription drug benefit (and actual legislation), but that legislation looks increasingly problematic as I write (for both political and moral reasons). So far as health status goes they are an extremely diverse group. More than half of them will spend less \$700 for health needs in any given year (while the per capita cost to Medicare is a bit over \$12,000.) What we tend to find in any given year is that the bulk of health costs for the elderly are concentrated in about 10% of that population. We also need to note that that \$12,000 per capita represents less than half the actual costs of health care for the elderly in any given year on average. The political significance of this should not be lost. If we “really” wanted to meet somewhat adequately the health care NEEDS of the elderly, we would have to nearly double tax revenues devoted to Medicare.....right now in 2008. That means an increase in Medicare costs from \$430 billion this year to about \$860 billion. BUT this is before the post-WWII “baby boom” generation becomes eligible for Medicare, starting in 2010, which will result in doubling the US elderly population by 2025 to around 76 million individuals over age 65!!!!

Oregon gained national attention in 1987 because it proposed an explicit, rational, deliberate approach to health care rationing. In this regard Oregon should be morally praised because they rejected the invisible approaches to health care rationing that seem to be the norm everywhere else. But Oregon in fact was subjected to a firestorm of moral and political criticism

for its efforts. The main criticisms were that it was the poor and disadvantaged who were going to be the victims of this rationing scheme (while middle class taxpayers and legislators were safely ensconced in their Blue Cross/Blue Shield), that rationing was not really necessary because Oregon could simply have taxed the middle class more heavily to raise the money needed to expand the pool of individuals who could be covered by Medicaid, and that morally invidious quality-of-life considerations were being used to determine whose life was not worth saving from the perspective of the limited budget of the state. In my article below I offer a qualified defense of Oregon and argue that Oregon's efforts were "just enough," something less than perfectly just, but clearly better than the Medicaid program that had been in place. Daniels will disagree with me. David Eddy will defend Oregon for the most part, and, I ask that you read his articles with special care because I think he offers a helpful perspective on the more general problem of how health care rationing can be accomplished most fairly in our society.

- Menzel, Paul. Strong Medicine, "The Poor and the Puzzle of Equality," 116-31. [A]
- Fleck, Leonard. "The Oregon Medicaid Experiment: Is It Just Enough?" Journal of Business and Professional Ethics, 9 (Fall, 1990), 201-17. [Note that the entire issue of this journal is devoted to papers analyzing moral issues connected with health care as a business.] [A]
- Jennings, Bruce. "Health Policy in a New Key: Setting Democratic Priorities," Journal of Social Issues, 49 (1993), 169-84. [A]
- Garland, Michael. "Health Care in Common: Setting Priorities in Oregon," The Hastings Center Report, 20 (Sept./Oct., 1990), 16-18.
- Garland, Michael. "Justice, Politics, and Community: Expanding Access and Rationing Health Services in Oregon," Law, Medicine, and Health Care, 20 (Spring/Summer, 1992), 67-81. [A]
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- Eddy, David. "What's Going on in Oregon?" JAMA, 266 (1991), 417-20. [A]
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- Oberlander, Jonathan and Brown, Lawrence. "Health Policy and State Initiatives," in Ethical Dimensions of Health Policy, edited by Marion Danis et al. (Oxford University Press, 2002), 184-201. [A] [Note: Kingdon and Oberlander/Brown are skeptics with regard to the utility of ethical argument and analysis in policy debates. You need to be prepared to respond to their arguments, which is why you need to read these essays.]

Here is another symposium issue of a law journal that is pertinent to our interests. This is entitled: **"Symposium: The Future of Medicare, Post the Great Society and Post Plus-Choice: Legal**

and Policy Issues.” Washington and Lee Law Review (Fall, 2003). Contributors include:  
**Oberlander, Jonathan.** “The Politics of Medicare Reform.”  
**Marmor, Ted and Martin, Spencer and Oberlander, Jonathan.** “Medicare and  
 Political Analysis: Omissions, Understandings, and Mis-Understandings.”  
**Harris, Dean.** “Beyond Beneficiaries: Using the Medicare Program to Accomplish  
 Broader Public Goals.”  
**Stanton, Thomas.** “The Administration of Medicare: A Neglected Issue.”  
**Kinney, Eleanore.** “Medicare Coverage Decision-Making and Appeal Procedures:  
 Can Process Meet the Challenges of New Medical Technology?”  
**Pauly, Mark.** “What if Technology Never Stops Improving? Medicare’s Future  
 Under Continuous Cost Increases.”

Aaron, Henry and Schwartz, William. "Rationing Health Care: The  
 Choice Before Us," Science, 247 (Jan. 27, 1990), 418-22.

Engelhardt, Tristram. "Why a Two-Tier System of Health Care  
 Delivery is Morally Unavoidable," in Rationing America's  
 Medical Care: The Oregon Plan and Beyond, edited by  
 Martin Strosberg and others, (Brookings, 1992), 196-207.

Evans, Robert G. "Illusions of Necessity: Evading Responsibility  
 for Choice in Health Care," Journal of Health Politics, Policy  
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Brown, Lawrence. "The National Politics of Oregon's Rationing  
 Plan," Health Affairs, 10 (Summer, 1991), 28-51.

Fox, Daniel and Leichter, Howard. "Rationing Care in Oregon: The  
 New Accountability," Health Affairs, 10 (Summer, 1991),  
 7-27.

Callahan, Daniel. "Ethics and Priority Setting in Oregon,"  
Health Affairs, 10 (Summer, 1991), 78-87.

NOTE: The debate about priority-setting has intensified over the past ten years; the volume of literature is enormous. It is important to note that this is not just an issue in the US; it is clearly an issue gaining increasing political attention in Canada and throughout Europe. The best single collection of essays of which I am aware is Priority-Setting: The Health Care Debate, edited by Joanna Coast, Jenny Donovan, and Stephen Frankel, all of the UK (Wiley, 1996), 278 pp.

#### **XIV. JUST CARING: MUST WE HAVE NATIONAL HEALTH INSURANCE? BENCHMARKS FOR FAIRNESS IN ASSESSING PROPOSALS FOR NATIONAL HEALTH INSURANCE**

This is intended to be a critically integrative class. Our focus is on broad health care policy as the key to just health reform, especially fair access and fair health care rationing.

Though we often think of ourselves as being attentive to the health needs of the poor in our society because we have the Medicaid program, the fact is that only 40% of the poor are eligible for Medicaid because of assorted restrictions imposed by various states. Moreover, there are 47 million Americans without any health insurance at all (the vast majority of whom are employed, but at low-paying jobs in 2008). For these individuals access to needed health care is sporadic and insecure at best. Further, apart from South Africa the United States is the only Western industrialized nation lacking a universal health care program. For most people in our society access to health insurance is tied to having a job with health insurance as a benefit. At one time this might have meant secure access to health care. Given large economic changes in the world and national economies, this is no longer a safe assumption. Changing jobs, for whatever reasons, typically means a window of exposure during which one's health coverage may be significantly diminished (if, for no other reason, because of pre-existing illness clauses in many health insurance contracts.) Is such a situation just, or even just enough?

There are a lot of ways in which we might hope to remedy this state of affairs. One would be to add a whole bunch of state or federal programs that would make sure that everyone had the opportunity to have some sort of health care coverage. This is patchwork reform, which, on the face of it, would mostly just reproduce the present pattern of inequities in access to health care, but at greater cost. At this point we need to note that, historically, the topic of national health insurance has been on the policy burner since the 1930s in the US. For the first several decades it was rejected as being socialistic or communistic, threatening too greatly the autonomy of physicians (both clinical and economic). It was rejected in the late 1970s as being too expensive for the federal government. Now, it seems, health insurance is too expensive for everyone. The implication of this last claim is that no proposal for universal health insurance will be taken seriously unless strong cost containment mechanisms are built into the proposal. All these concerns are reflected in the shape of the latest proposals put forth for various kinds of national health insurance, more accurately, approximate national health insurance.

One proposal that got a lot of attention in the early 1990s was the Enthoven-Kronick proposal, which would have everyone covered under either a public or privately sponsored HMO (managed care plan). These plans would offer different types of packages, mixes of services at various price levels. Plans would have to compete successfully for members or go out of business. The poor would be given health vouchers with income-adjusted (maybe health-adjusted) values that would allow them to purchase some sort of health plan (not at the high end, however). Competition is what is supposed to contain costs. This would be a multi-tiered health system since there would be many different health packages. Plans would be regulated, and there would be a minimal package of services that would have to be provided by

each plan. Would this be just enough?

A second proposal we will examine is the Canadian system of national health insurance. This is seen as a promising model because the Canadians seem to have a very efficient health system of very high quality that covers everyone with essentially the same package of health services. Further, the Canadians spend only 9-10% of GNP on health care compared to the 16.2% we spent in 2007 on health care [\$2.3 trillion]. They achieve the bulk of their savings by having a single financing system, as opposed to the 1500 health insurance plans we have in the United States with their enormously complex and differentiated benefit packages. Does justice require that we adopt a system of health financing as comprehensive and equitable as what exists in Canada? Or does their system represent some degree of social beneficence, which might not be strictly required of us?

The Canadian system is not without its stresses and strains. The biggest single problem is the upward push on costs that is exerted by constantly expanding medical technology. This is certainly not a pressure that is unique to the Canadian system. However, as we shall see in the article by Lomasky, when there is a single universal system for health care financing, then rationing decisions at the macro-level are very visible, and are likely to be sources of intense and divisive public debate. Hence, Lomasky will argue that the best reason for avoiding any single financing mechanism for health insurance is that tragic rationing choices are highly visible. The Lomasky paper is also important because he will argue that any form of national health insurance is fundamentally illiberal. That is, individuals will be forced to pay for health care services for others which they consider morally abominable. The most obvious example is abortion, but there is quickly emerging an enormous range of other health services that will be equally problematic for specific religious groups, such as various kinds of infertility treatments and various sorts of genetic manipulations. In my paper on national health insurance I respond to most of these objections by Lomasky.

We will also examine the Clinton Administration proposal for health reform, which in many respects is a blend of the Canadian model and the managed competition approach of Enthoven/Kronick. Among other things we will critically examine is the paper our group, #17, prepared in Washington in which we attempted to articulate a moral vision for health reform. That paper (in published form) is the JAMA piece listed below as authored by Brock/ Daniels. More recently, there is the libertarian approach to changing the way in which health care is financed, which is expressed in the form of Medical Savings Accounts [MSAs] tied to individuals, partially funded by employers and/ or federal/ state government in the case of the poor. The MSA approach is highly individualized in the way that Menzel (maybe) and Lomasky would applaud.

For purposes of having a coherent perspective to organize our discussions around, my recommendation would be to start by reading carefully the Brock/Daniels/ Working Group #17 paper. **The question we can ask ourselves is this: Are the values listed there sufficient to identify more or less morally defensible approaches to reformed health care financing?**

**That is, could someone justifiably claim that that value scheme is skewed to "fit" the Clinton reform plan; and hence, it does not represent a fair and impartial normative scheme for assessing competing proposals? If so, what values are missing to develop a fairer scheme? Or what values ought to be deleted?** We do not have the time to get into all the nitty-gritty political details associated with various proposals, but there are some that have been central to recent political debates. One such detail is the inescapability of competition as a mechanism for controlling overall health care costs. The Clinton Administration saw this as a virtue of their proposal, adding to its feasibility (at least as long as the competition was 'managed' or regulated. Others would see this as a moral flaw that would make virtually impossible even a stable approach to achieving a more just health care system. What sort of judgment would you be inclined to make, and why? What we have today in our health care system may be properly described as "unmanaged competition." This clearly can have a high price, morally and psychologically. When I taught this seminar a couple offerings ago or so [Jan., 2000] Pilgrim Health Plan in Boston, often seen as a model form of managed care, was looking at a 1999 deficit of nearly \$200 million; and the prediction that this plan will fail, thereby leaving 1.3 million plan members to fend for themselves. Many plans have in fact failed with a range of disastrous consequences for patients attached to those plans.

Let me offer one further observation regarding competition in health care. Often ideology drives the belief that competition will yield great efficiencies and the effective control of escalating health care costs. This is an economic truth in virtually every sector of our economy except health care. In health care competition typically takes the form of local hospitals ALL wanting the very latest in the way of extraordinarily expensive new technologies, thereby assuring that not enough patients will use those technologies, which means sunk costs have to be spread out over a smaller base. Just a few weeks ago (April, 2008) there was a story about FIVE hospitals in Michigan EACH wanting to invest \$160 million to build one of these proton beam accelerators used to treat prostate cancer with exquisite precision (maybe other cancers as well). None of these hospitals would allow any of their "competitors" to have one of these devices by themselves, thereby capturing "all that business." These systems would have annual multi-million dollar maintenance costs as well. Each treatment would cost at least \$50,000. How should a just and caring society with limited resources address this problem?

I will give you a quick summary of the German system (or other European systems). All of them must deal with the rationing problem for many of the same sorts of reasons we must address it. However, they devote a much smaller fraction of their GDP to health care, Germany and Canada both being around 10% of GDP. One major reason for this discrepancy is that we have extremely high "administrative costs" for our health care system because it is so fragmented, so private, and so driven by the profit motive at critical junctures. Himmelstein and Woolhandler are two physicians who have done the most research in this area (mostly published in the New England Journal of Medicine. The "most conservative" estimate of our "excess administrative costs," (relative to Canada or Germany) is ten percentage points. That represents about \$230 billion in 2007 that could otherwise have gone to patient care for the uninsured. The political challenge of actually reaping those savings is unimaginable because we are talking about \$230 billion in entrenched economic interests. I should also point out that there is another \$100-\$140

billion that would be available for the uninsured if the middle class were denied the “tax exclusion” for their health insurance. That means that I pay no federal or state income taxes on the \$11,000 value of my MSU health insurance package. If the uninsured are able to purchase private health insurance, they must do that with after-tax dollars. It looks like there is a serious injustice here as well, though again, few in the middle class would be willing to see themselves pay a couple thousand dollars more per year in taxes (giving up the tax break) for the benefit of the uninsured. **The bottom line questions are these: How much “inefficiency” and “inequality” in access to services should a just and caring society tolerate in order to approximate some form of national health insurance? Also, what should the content be of a “minimally decent health insurance package” that we would be morally obligated to guarantee to all in our society? And would it be morally tolerable to continue to have the Medicare and Medicaid programs as distinct programs for the elderly and the poor as part of some sort of national health insurance scheme? That is, would such a system still be too inequitable to be judged even non-ideally “just enough?”**

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Internal Medicine, 637-61. **NOTE: It is significant that some major physician groups have endorsed comprehensive national health insurance. This is for a mix of self-serving and altruistic reasons. Other physicians strongly endorse medical savings accounts; but those are for mostly self-serving reasons (since individuals with personal accounts would have no bargaining power regarding fees and prices).**

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Changing to National Health Insurance, edited by Robert Huefner and Margaret Battin [part of the series "Ethics in a Changing World," (University of Utah Press, 1992).

Patient Power: Solving America's Health Care Crisis by John Goodman and Gerald Musgrave (Cato Institute, 1992). This volume reflects primarily a libertarian perspective on health reform.

Just Doctoring: Medical Ethics in the Liberal State, by Troyen Brennan (California University Press, 1992).

It would certainly be an understatement to say that the literature on national health insurance and health reform is voluminous at this time. Here are a few items you ought to be aware of that I believe are essential for your own thinking on this topic.

In general, there are a few health policy journals that philosophers ought to read regularly if they wish to be part of the health policy debates and comment intelligently on them. These journals include Health Affairs, The Milbank Quarterly, The Journal of Health Politics, Policy, and Law, American Journal of Law and Medicine, and Law, Medicine, and Health Care Ethics. All of these journals have had special issues largely or entirely devoted to the topic of health reform. For example, Health Affairs had a spring "supplementary" issue (1993) titled "Managed

Competition: Health Reform American Style," which will give you a good understanding of the range of issues and proposals out there that fall under the rubric of "managed competition." Likewise, there are a number of useful articles in the American Journal of Law and Medicine, 19(Numbers 1/2, 1993). The theme of this issue is "Implementing U.S. Health Care Reform." Then in the Journal of Health Politics, Policy, and Law they have two complete special issues under the title "Health Care Reform: Lessons from the Past: Prospects for the Future." These are their Summer and Fall (1993) issues. You might also note that there have been at least ten law journals that have done special issues in the recent past on health reform and related issues. Likewise, you will find leading medical journals with solid critical discussions of these issues. The two you should certainly pay attention to are The New England Journal of Medicine and The Journal of the American Medical Association. Again, an extremely helpful contribution from JAMA on the issues of health reform is a paperback volume they published titled Caring for the Uninsured and Underinsured (1991). Below I list three articles that represent well the kind of "ancillary thinking" you must be able to do to respond effectively as a philosopher to the challenge of health reform. I have also attached to the this syllabus a couple tables of contents from recent thematic issues of the Journal of Health Politics, Policy, and Law which philosophers writing in this area should be aware of. More recently (2002—2005) the **Institute of Medicine** has published a series of volumes addressing different dimensions of the broad problem of health care reform.

Light, Donald. "The Rhetorics and Realities of Community Health Care: The Limits of Countervailing Powers to Meet the Health Care Needs of the twenty-First Century," 105-45.

Emanuel, Ezekiel and Emanuel, Linda. "Preserving Community in Health Care," 147-84.

Frankford, David. "The Normative Constitution of Professional Power," 185-221.

All three articles are from the Journal of Health Care Politics, Policy, and Law, 22 (Feb., 1997).

## **ADDITIONAL TOPICS:**

There are numerous other issues of health care justice that we did not have time to consider. I mention the following issues to you in case any seminar members might choose to pursue them in a final paper for the course.

### **Just Caring: Health Care Rationing and Physician-Assisted Suicide**

Sulmasy and others have claimed that the sort of rationing that is inherent in managed care is very likely to increase pressure for access to physician-assisted suicide in end of life circumstances. He sees the loyalty of physicians to their dying patients undermined in subtle ways as physicians convince themselves (self-deceptively) that it would be kinder to encourage a quicker death in their patients than force them to endure a drawn out dying process. Even hospice care would be subverted, since there are significant and recently increasing expenses associated with such care. Therefore, Sulmasy concludes that this increased risk of desires for physician-assisted suicide warrants rejecting managed care and the rationing associated with it. I believe this line of argument is flawed; and I have presented a strong line of counter-arguments in an article of mine, “Just Caring: Assisted Suicide and Health Care Rationing,” University of Detroit Law Review 72 (1995), 873-899.

### **Just Caring: The Moral Challenge of Fair Access to Experimental Medical Research**

The key issue in this chapter is: How do we determine as a just and caring society what counts as just access to experimental medical research, especially when individuals are faced with death or needless suffering or permanent injury/ disability if they are denied access to such research? Should access to such medical opportunities be seen either as entirely a matter of markets and ability to pay, or as a matter of social beneficence, not a matter of justice at all, the underlying idea being that no one has a just claim on any medical research? Or, if we do believe there are matters of social justice here, then are we justified in compromising what we might call our egalitarian intuitions in these circumstances for the sake of improving the reliability of the research that is done? That is, are we justified in excluding some patients with the relevant medical needs from some research trials (though they are then doomed to death) because they have co-morbid conditions that are likely to “contaminate” or “compromise” the scientific integrity of the data that results? That is, if we see this as primarily a utilitarian rationale [we do this for the sake of all future patients who will then know what will really work and what will not], then is this a situation in which our utilitarian judgments justifiably override egalitarian considerations?

There is another large issue that needs to be addressed, namely, whether there are considerations of justice that ought to control the dissemination of “still somewhat experimental” medical technologies. A recent painful example pertains to the dissemination of ABMT in connection with the treatment of breast cancer when prior therapies have failed. The technology has seeped into the marketplace and into the clinic for lots of reasons long before we have what would seem to be a reasonable degree of medical certainty regarding its efficacy or appropriate medical circumstances for its use. This has generated all manner of inequities among women who

are in advanced stages of breast cancer. This technology had costs of \$100-\$150,000 per case for what was claimed to be a 10% chance for three-year survival. But by 2000 it was clear that this very costly technology offered no survival advantage over much less costly alternatives, though it took ten years to acquire this knowledge (due largely to the fact that women would NOT enroll in controlled clinical trials due to the fact that their access to the technology would be only 50%).

Callahan, Daniel. What Price Better Health? Hazards of the Research Imperative (University of California Press, 2003).

Callahan, Daniel. False Hopes: Why America's Quest for Perfect Health is a Recipe For Failure (Simon and Schuster, 1998).

Lo, Bernard. "Values in Research: Picking Research Priorities Ethically," in Ethical Dimensions of Health Policy, edited by Marion Danis et al. (Oxford University Press, 2002), 337-54.

### **Just Caring: The Moral Challenges of Personal Responsibility for Failing Health**

There is a very large range of health care needs that at least in part come about because of decisions individuals have made for which they might be thought to be personally (morally) responsible. These health needs are often associated with what we culturally judge as "bad habits," smoking, illegal drug use, excessive consumption of alcohol, bad eating habits, various sexual practices, injury associated with bad driving or excessively risky sports, etc. More specifically, there has been research on one large category of patients, referred to by Zook and Moore as RHSDs, or Repeated Hospitalization for the Same Disease. This includes a broad range of non-compliant patients, such as diabetics, or individuals with COPD who continue to smoke, or cardiac patients in CHF who are non-compliant in various ways, etc. The justice issue we need to address is: Do any of the above individuals have diminished just claims to needed health care? May they justly be given lower priority in competition for scarce and expensive life-prolonging resources, such as ICU beds or liver transplants, etc., than patients who have been reasonably attentive to their health, and whose health problems have come about "through no fault of their own"?

### **JUST CARING: PRIORITY-SETTING AND PUBLIC HEALTH**

This is another topic that we will likely not be able to discuss in the seminar itself. But it has been gaining increasing attention in debates about health care justice, in part because it has generally been ignored as a result of a focus on acute and chronic health care interventions.

Powers, M. and Faden, R. 2006. *Social Justice: The Moral Foundations of Public Health and Public Policy*. New York: Oxford University Press.

Buchanan, D. 2008. "Autonomy, Paternalism, and Justice: Ethical Priorities in Public Health." *American Journal of Public Health* 98 (1): 15-21.

**JUST CARING: WHO IS RESPONSIBLE  
FOR INTERNATIONAL HEALTH NEEDS?**

This is yet another topic that we might not be able to say much about in the seminar itself, but it might be a good focus for a seminar paper. In the required books for the course a number of chapters address different aspects of this topic.

## APPENDIX MATERIAL

### JUST CARING: RATIONING, LAST CHANCE THERAPIES, DISABILITY, AND THE ROLE OF RATIONAL DEMOCRATIC DELIBERATION

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College of Human Medicine, Michigan State University

**Instructions:** You will be given a series of case scenarios and policy options below. For each of these you will respond using your computer keypad on a five-point scale:

- A. Strongly Agree**
- B. Agree**
- C. Unsure**
- D. Disagree**
- E. Strongly Disagree**

We saw in late 2001 the successful development of a Totally Implantable Artificial Heart [TIAH]. It has been implanted in seven patients on an experimental basis. All were expected to die within 30 days. Two survived nearly a year. In early 2008 clinical trials are underway in which at least 100 of these devices will be implanted in individuals. In the US there are 350,000 people per year who could benefit with five extra years of life on average if they received a TIAH. The cost of such transplants would be \$300,000 each (2007\$). About 70% of these individuals are over age 65. This one device alone would add \$100 billion to the cost of health care per year if 350,000 of these were done. The dissemination of this device would cause enormous moral and political problems.

1. If we had the opportunity to have some sort of national health insurance in the US that covered everyone [47 million currently uninsured] by the year 2009, then the TIAH ought not be a covered benefit in that plan. The moral judgment I would endorse is that it is morally preferable to provide a good package of health benefits for everyone before there is any public funding for the TIAH.
2. I would also endorse the judgment that it is morally permissible that individuals who could afford the \$300,000 cost from their own pocket (or supplementary insurance) ought to be allowed to buy it. No one is made worse off as a result of such purchases as long as no tax deductions are given for these purchases.
3. There are very substantial unmet health needs associated with persons with a range of disabilities. I believe a just and caring society ought to make certain those needs are met BEFORE there is any social spending to provide artificial hearts (even if this means some

relatively young individuals would die for lack of timely access to an artificial heart).

4. Everyone should have the opportunity to achieve a normal life expectancy if that is medically possible. Therefore, we ought to produce 100,000 TIAHs per year that would only be available as a covered benefit to those under age 70. This is just enough and caring enough, given other urgent medical needs.
5. In general, I would endorse as morally just severely limiting access to costly life-prolonging medical technologies for those over age 70 so long as the savings thereby achieved were redirected to meeting the health needs of younger individuals with a broad range of disabling conditions for which costly amelioration/ functional restoration was available (example: myoelectric arms at \$70K each).
6. I would endorse as morally just #5 **only if** the money saved by denying the elderly expensive life-prolonging care were used for **life-prolonging goals** of younger individuals with otherwise life-shortening disabilities.
7. I would **not endorse** as morally just the elderly rationing protocol in #5 if the money saved were used mostly for quality-of-life enhancing purposes among a range of younger persons with disabilities.
8. There is intense debate now in the US about a Medicare prescription drug benefit. The ten-year cost of that benefit would likely be at least \$800 billion (which would only cover 25% of drug costs for the elderly during that period). If the artificial heart were a covered Medicare benefit, annual costs would be \$55-65 billion. If we had to choose between covering the TIAH under Medicare or the prescription drug benefit, then the fairest choice would be the prescription drug benefit.
9. In November of 2001 the New England Journal of Medicine reported the results of a trial in which 68 individuals in end-stage congestive heart failure received the left ventricular assist device [LVAD]. Patients in heart failure survive an average of 5 years. There are 5 million such patients in the US. We add 550,000 to that number each year. The patients in this trial had predicted survival of only six months to one year if nothing was done. Two years after implantation of the LVAD 77% had died. The cost of implantation is about \$180,000 each. The cost per life-year saved is about \$90,000. I believe that a just and caring managed care plan/ Medicare/ Medicaid ought to include the LVAD as part of its basic benefit package. It's morally wrong to allow these individuals to die if we can give them an extra year or two of life which they want. NOTE: We could do at least 200,000 of these procedures each year, which would add \$36 billion each year to health care costs in the US.
10. More patients who have serious heart attacks are surviving those heart attacks. But they are surviving with the "risk" of suffering an arrhythmia that could be fatal. A relatively new device, the cardiac defibrillator can be implanted in an individual to "shock" a heart into a normal rhythm. Dick Cheney has one. The cost is \$40,000 for the device and surgery. Last

year we implanted 220,000 of these devices. It is projected that we will implant 400,000 per year in four more years, which would add \$16 billion to the cost of health care in the US. This is clearly an effective device; a just and caring managed care plan/ Medicare/ Medicaid ought to cover this as part of a standard benefit package. We ought not let people die from arrhythmias that are preventable and correctable. NOTE: The primary reason there is an issue here for discussion is that 81% of these devices never fire over a five-year period of time (because the person with the device fails to have an arrhythmia). The battery needs to be changed at five years at a cost of about \$20,000 (not your ‘bunny batteries’). Only 10% of these devices fire and save someone from death at that time.

11. When I think about all these interventions around potentially fatal cardiac events, I realize we must make hard choices. I would endorse as a reasonable, just, and caring trade-off having my managed care plan [or Medicare] support access to cardiac defibrillators but deny access to both LVADs and TIAHs at plan expense.
12. If an individual is 60 yrs old and in a persistent vegetative state (PVS), and if they are at risk of dying as a result of a heart arrhythmia, then I believe they have just as much a just claim to an implantable defibrillator at a cost of \$40K as Dick Cheney.
13. If an individual is 60 yrs old and in the advanced stages of Alzheimer’s (as Reagan was for the past four years), and if they are at risk of dying as a result of a heart arrhythmia, then I believe they have just as much a just claim to an implantable defibrillator at a cost of \$40K as any other person with a similar cardiac problem.
14. If an individual is 60 yrs old and has been a vent-dependent quadriplegic for the past ten years, and if they are at risk of dying as a result of a heart arrhythmia, then I believe they have just as much a just claim to an implantable defibrillator at a cost of \$40K as any other person with a similar cardiac problem.
15. If an individual is 50 yrs old and has Down’s Syndrome, and if they are at risk of dying as a result of a heart arrhythmia, then I believe they have just as much a just claim to an implantable defibrillator at a cost of \$40K as any other person with a similar cardiac problem.
16. Many individuals with Down’s Syndrome may be able to work only at relatively low-wage jobs with no health insurance. If such an individual develops a heart arrhythmia at age 50 (as above) and needs an implantable defibrillator to prevent sudden death, then it would be unjust to create a special public policy that would pay for defibrillators for persons such as that while other uninsured individuals with cardiac problems had to accept the risks of sudden death without public help.
17. Herceptin is a cancer therapy for the roughly 25-30% of women with metastasized breast cancer who have HER-2 receptors, which cause their cancers to progress much more

readily than women lacking these receptors. A course of Herceptin will cost about \$70,000 and, according to a study in NEJM [March 15, 2001]] will yield on average only five extra months of life expectancy for these women. This gain in life expectancy is too marginal relative to the cost and alternative interventions for breast cancer. Therefore, no one is treated unfairly if this is not a covered benefit within our managed care plan/ Medicare. We would do this both for the sake of equity and to control costs.

18. A just and prudent society with only limited resources to meet virtually unlimited health needs should shift cancer care dollars to prevention and to aggressive treatment of earlier stages of the disease when there is a greater likelihood of a good outcome. To generate these resources in our managed care plan/ Medicare we ought to have as a policy withholding aggressive and expensive cancer interventions from individuals for whom we can confidently judge they have less than a 10% chance of surviving another year. I would endorse such a policy as being just and caring.
19. I would not endorse the policy in item #18 unless it was restricted to individuals over age 65, i.e., persons who have had the chance to live most of a life. A just and caring society is morally obligated to spend more to save and prolong the lives of relatively younger individuals who have not had the chance to live a full life.
20. About 210,000 patients die of sepsis each year in the US. In a recent report in NEJM [Sept. 26, 2002] it was found that when recombinant human activated protein C [Xigris/ Lilly] is given to patients with severe sepsis and greater severity of illness [APACHE II scores of 25 or more, no cancer, age less than 80] there was a 6% increase in lives saved compared to current therapy. But this drug costs \$7000 per course of treatment. This yields cost-effectiveness results of \$28K per year of life gained, \$47 K per QALY gained for the treated cohort of patients. Though a marginal chance of benefit exists for severe sepsis patients with APACHE scores below 25, the cost per life-year gained for that larger cohort would be \$575,000. It is not unjust to deny Xigris to patients with severe sepsis whose APACHE II scores are below 25.
21. Michael S was born with necrotic small bowel syndrome to uninsured teen parents. Initially his life was sustained on TPN for six months at a cost to the hospital of about \$250,000. But the hospital was faced with a serious and sustained financial crisis. The CEO approached the attending physician and explained the hard choices he faced. If Michael remained at the hospital until liver failure from the TPN, the hospital faced costs of \$1-\$2 million. A local nursing home would take Michael, and care for him until he died in two weeks. If the physician insisted on keeping Michael, then the CEO would have to shut down the ER to all indigent patients except for true emergency care. Given these awful choices, it would not be unjust to allow Michael to die in order to protect access to the ER for the poor and uninsured.

22. There are 6000 infants born each year with necrotic small bowel syndrome in the US. Their lives can be saved for four years with hyperalimentation, which costs \$300,000 per year per child. But the hyperalimentation that saves their lives will also destroy their livers, which will cause death at age four. We can save their lives for two more years if we do a liver transplant at a cost of \$250,000. We can also prolong their lives for some brief period of time with a total bowel transplant at a cost of \$600,000 per transplant. A just and caring community is morally obligated to fund these medical interventions as part of its commitment to the well-being of its poor and vulnerable citizens.
23. While it is regrettable that these children are afflicted with small bowel syndrome and, are doomed to die, the cost of saving each cohort of these children is \$3 billion. If we saved each cohort for four years, that would mean annual costs to our health care system of \$12 billion. There are higher priority health needs for children (such as children with a range of disabilities who could benefit with more health care resources) that have a more just claim on these resources. Therefore, a just and caring community with only limited resources for meeting health needs should simply allow these children to die at birth.
24. Protease inhibitors (as part of triple therapy) for AIDS have costs of about \$15-20K per patient per life-year saved. These aggregated costs are now in the vicinity of about \$14 billion in the US. Though these are high health care costs, this is an effective life-prolonging therapy for mostly younger patients that a just and caring society ought to underwrite.
25. Protease inhibitors are now failing for many patients with AIDS. But fusion inhibitors may be equally successful in controlling HIV replication, though their cost raises to \$35K per patient per year the cost of each life year saved. Still, a just and caring society is morally obligated to underwrite these costs, especially if these drugs are as effective in prolonging life as the protease inhibitors. Aggregated annual costs could rise to \$30 billion per year over the next five years.
26. Last year of life costs can be very high for AIDS patients, and several other chronic degenerative disorders. Trade-offs are needed to establish more just and more prudent allocations of health care resources. I would endorse the following society-wide rationing protocol: If I have been the beneficiary of multi-year expensive life-prolonging medical care (say, greater than \$250K), then I would deny myself very expensive last year of life care if there is reasonable medical certainty that I had less than a 20% chance of surviving one year.
27. Angel Diaz is 69 years old with very advanced Alzheimer's. He had been a machine operator and part-time minister in Philadelphia. [Wall Street Journal, Sept. 12, 2003]. First signs of AD were in the early 1990s. His brother cared for him until May 2002 when Angel choked on some food and required emergency hospitalization. He emerged vent dependent

and with a feeding tube, was discharged to a nursing home. In Feb of 2003 Angel developed pneumonia and intestinal bleeding. Since then he has spent 140 days in the hospital at a cost of \$280,000 only half of which is covered by insurance. Given Mr. Diaz's overall debilitated state, he has no just claim to this level of health care. It would not have been unjust if, back in February, he had been given palliative care only and allowed to die.

28. There may be 300,000 patients in the United States who are in the end stages of Alzheimer's Disease in any given year. In any given year they are likely to be afflicted with a potentially life-threatening pneumonia or a cardiac arrhythmia or other such event. If we had as a social policy the non-treatment of such life-threatening illnesses in these circumstances, and if we saved \$30B per year in care costs, and if this \$30B were redeployed to meet other health care/social service needs of the elderly where more good was likely to be accomplished, then a just and caring society ought to endorse such a policy.
29. Patient "H" is 20 years old with severe hemophilia A. He has been cared for at a large medical center in Boston for the past ten years. His hemophilia is complicated by the fact that an inhibitor problem developed when he was very young. This means factor 8 cannot be used to treat bleeding episodes. Other alternatives must be used that have less consistent results. Mr. H now has chronic joint disease with gradual loss of function. Bleeds have become more frequent, in part as a result of the disabilities. Treatment requires prolonged hospital stays and long rehab. Mr. H's physician states that hemophiliacs who have inhibitors can be tolerized by exposing them to daily high doses of factor 8 over a prolonged period of time. This tricks the immune system and the inhibitor disappears. Ideally, this therapy is used with very young patients with a 70-80% success rate. In the case of Mr. H predicted success would be 30-40% because he is so far out of the window of opportunity. This would be an eight-month course with a cost of \$5 million. After that (if successful), yearly costs of factor 8 would be \$100,000 plus hospitalization and rehab costs. Mr. H has an extremely supportive family. Assume that the state of Massachusetts would absorb all these costs. Given all the pressures and shortfalls for state budgets, and given all the other unmet care needs for young people (especially those with disabilities) in the state, this patient has no just claim to \$5 million worth of care with such a low prediction of success.
30. If this hospital had a charity care budget of \$100 million, it would be unjust (relative to all the other claims on that budget) for \$5 million to be used for one patient, especially if there is only a 1 in 3 chance of success.
31. \$5 million would pay for fusion inhibitors atop triple therapy (\$35K each) for 150 AIDS patients for one year. From the perspective of health care justice, I believe we would be morally obligated to direct these dollars to these AIDS patients rather than Mr. H.

32. With \$5 million we could pay to sustain the lives for one year of fifty patients such as Angel Diaz, i.e., advanced Alzheimer's disease and potentially life-threatening medical problems. If this was my choice, then I believe the norms of health care justice would be better met by spending this money on Mr. H rather than fifty patients like Mr. Diaz.
33. Imagine that we have twenty patients below age 70 with failing hearts [age range 50-69]. All will be dead within a year. With \$5 million we can save all of them for, on average, five extra years by providing them with an artificial heart. From the perspective of health care justice I believe our first priority with these funds ought to be to sustain the life of Mr.H.
34. One morally important feature of the case of Mr. H is that we are not dealing with a true "last chance" therapy. There are alternative therapies that will sustain his life, though their use will likely result in continued deterioration in his functional capacities and overall quality of life. Still, this is another reason for saying that no obligation of justice is violated by failing to provide him with this therapy.
35. There are about 6000 children born each year in the US with hemophilia. If the vast majority of these children must rely upon public dollars or charity care to get the health care that they need, and if the average cost to save a life-year for these children is \$100,000, then fifty of these life years can be paid for with that \$5 million. From the perspective of health care justice I see this as another reason why it would be unjust to spend this money on Mr. H.
36. Myoelectric arms for amputees have costs of about \$70,000. They provide much more in the way of functional restoration than other alternatives. From the perspective of health care justice I believe we would be morally obligated to fund fifty of these instead of underwriting the \$5 million cost of experimental therapy for Mr. H. That is, we should think of those prosthetic arms as having higher priority from the perspective of health care justice.
37. Roughly an equal number of babies are born each year in the US who have hemophilia and who have necrotic small bowel syndrome. If we had one billion dollars per year to sustain the lives of individuals in either cohort, then health care justice would justify using all that money for the benefit of the children with hemophilia (who could look forward to quite long life expectancy on average) as opposed to the infants with small bowel syndrome.
38. We could imagine that Mr. H is an extremely rare sort of case, one in a thousand among hemophiliacs. If that were true, then there might be a moral argument that would justify

spending \$5 million on him for this intervention. However, 15% of hemophilia patients each year would be in this same category, roughly 1000 individuals. If Mr. H has a moral right to this therapy, then justice would require offering it to the other 999 as well, which would result in aggregate annual costs for this cohort alone of about \$5 billion.

39. Prior to 1970 hemophiliacs had a life expectancy of about 10-20 years. Today they can achieve an average life expectancy in the mid-60 range, though there are very high social medical costs attached to making this possible. As with dialysis patients and HIV+ patients we have annually increasing cohorts of survivors with very high annual costs to sustain those lives. For hemophiliacs those annual aggregated cost increments will be in excess of \$1 billion in constant dollars. A morally significant feature of hemophilia is that it is genetically transmitted. Given the need to control health care costs over the very long run, it would be neither unjust nor otherwise morally objectionable to require that individuals with hemophilia who choose to have children use alternate reproductive mechanisms (IVF with a sperm donor, or preimplantation genetic diagnosis) to minimize the birth of future children with hemophilia.
40. If an individual has been blind from birth, and if advances in embryonic stem cell research prove capable of restoring sight to most of these individuals at a cost of \$100K per intervention, then this should be regarded as a higher priority health need from the perspective of health care justice than sustaining the lives of patients in PVS or the most advanced stages of Alzheimer's.
41. If an individual has become either a paraplegic or quadriplegic (perhaps as a result of an auto accident), and if advances in embryonic stem cell research prove capable of restoring a substantial degree of motor function at a cost of \$100K per intervention, then this should be regarded as a higher priority health need from the perspective of health care justice than sustaining the lives of patients in PVS or the most advanced stages of Alzheimer's.
42. I would endorse a fair equality of opportunity account of health care justice for setting health care priorities. This means higher priority for resources ought to be given to health care interventions that restore major functional capacity (even if very costly) over those interventions that are likely to offer only minor functional restoration or only a small chance of major functional restoration.