



## Genetics and Ethics: A Community Dialogue

by Leonard Fleck

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We are beyond the age of genetic innocence. We are entering the age of genetic responsibility. Through the Human Genome Project and its spin-off technologies we are rapidly gaining the knowledge and the power to make genetic choices. Our task is to make those choices in a reflective and responsible manner that enhances and preserves our common moral and political heritage.

The University of Michigan and Michigan State University are recipients of a grant from the National Institute of Health Human Genome Project ELSI (Ethical, Legal and Social Implications) program. The purpose of the grant is to explore the ethical, legal, and policy implications of emerging genetic knowledge and technologies. What is distinctive of this project is that we are addressing these issues through community forums that are rationally and democratically deliberative. Our working assumption is that the moral and political challenges generated by emerging genetic technologies need to be resolved through reflective community dialogue that balances conflicting values.

At least four general value issues are raised by this emerging knowledge. First, how expansive (unregulated) should the domain of reproductive liberty with respect to genetic screening be? Second, how expansive should the domain of reproductive privacy with respect to genetic screening be? Do individuals, for example, have a very strong right to genetic privacy such that they are not morally obligated to reveal to a potential marriage partner that they have the Huntington's gene, or that there is a 50% chance that they have that gene and will be afflicted with that disorder around age 40?

Third, to what extent is society morally obligated as a matter of justice to make sure that all in our society are assured some level of effective reproductive liberty with respect to genetic testing? Genetic testing has economic costs. Do those who are less well off have a just claim to societal subsidy for genetic testing so that they have *effective*, as opposed to merely *symbolic*, reproductive liberty comparable to that of the middle class?

Finally, how should we operationalize, in both moral and policy terms, the concept of genetic responsibility? To what extent will our concept of genetic responsibility constrain the reproductive choices of individuals? Should such constraint be a matter of moral practice only, or should it be operationalized in professional and/or public policies?

We have carried on the community dialogue project in seven Michigan communities, including Lansing. At each site 40-50 individuals participated in a series of six 2-hour community dialogues. In the fall we explored a range of issues related to genetics and reproduction from an ethical point of view. This spring we are exploring the same range of issues from a policy perspective.

The dialogue began in each community with a series of about fifty scenarios that raised various ethical problems related to genetics and reproduction. Each scenario also expressed a suggested moral judgment which participants responded to on a five-point "strongly agree/

strongly disagree” scale. A computer instantly aggregated those responses and displayed a bar graph that all could see. These preliminary judgments became the “raw data” for discussion that followed.

Summarized below are the major moral issues that emerged from the dialogues. These conclusions were elicited by surveying the participants following the dialogues.

1. We ought to protect the genetic privacy of individuals. Individuals should have a strong presumptive right to protect genetic information about themselves from disclosure to others.

2. Any individual’s right to privacy should be limited when it adversely affects the equally important rights or interests of others. There are some genetic facts that we are morally obligated to reveal to potential spouses and sometimes siblings, but generally not to employers or insurers.

3. Though I might have a right not to know certain genetic facts about myself (because it might prove to be too painful), I may not be morally justified in exercising that right if the serious welfare interests of future children are put at risk (i.e., if the children would be vulnerable to serious medical problems early on in life as a result of their genetic inheritance).

4. The genetic privacy of children ought to be respected when there are no therapeutic goals to be achieved by parents having that genetic information.

5. Individuals who intend to marry and have children are not morally obligated to undergo a battery of genetic tests to define their genetic endowment and to identify any genetic risks they might pose to their future possible children. (Comment: This statement is not entirely congruent with the statements about genetic responsibility in conclusions 2 and 3. This might have to do with the implied breadth of genetic testing suggested by the item. There may be only a limited range of genetic conditions that individuals would be morally obligated to be knowledgeable about.)

6. Parents should be morally free to pursue whatever alternate reproductive technologies are available to avoid the birth of a child with a serious genetic disorder. (The implication of this judgment is that such technologies are not intrinsically morally flawed.) Note: This judgment was generally endorsed at the 70%+ level, though in a couple communities this slipped to 60%.

7. Roughly 65% of the respondents rejected the notion that society ought to subsidize these alternate reproductive technologies for individuals who wanted to use them to avoid the birth of a child with a serious genetic disorder. The subsidy stated in the item was 50% of costs. About 20-25% of respondents thought there ought to be such a societal subsidy.

8. Sixty-five percent supported the idea that couples ought to have the right to access pre-implantation genetic diagnosis and in vitro fertilization in order to avoid the birth of a child with cystic fibrosis (although there was considerable variation across communities). This technology requires the creation of multiple eight-celled embryos, some of which will be discarded. This factor seems to have been the source of much moral disagreement on this item.

9. Sixty-five percent rejected the notion that pre-implantation genetic diagnosis represents a form of invidious discrimination against individuals with disabilities, though, as in the prior item, there was considerable variation across communities.

One goal is to demonstrate a model of political dialogue about very controversial moral issues that is preferable to the interest group lobbying and diarrhetic rhetoric that is too often the norm. In the concluding portion of this essay, let me briefly describe the main features of that model of political dialogue. First, the primary theoretical problem we are addressing is this: What conditions must be met in order to justifiably invoke *rational democratic deliberation* to yield morally and politically legitimate judgments and public policies regarding genetics and reproductive decision making?

Second, a key subsidiary problem is how to demarcate the "space of individual liberty" from "public space" in the matter of genetics and reproductive decision making. "Public space" is political space in which decisions are legitimately constrained for the sake of protecting some range of public goods or interests. It is also the space within which trade-offs are made among public goods, or between public goods and individual interests. "Individual liberty space" is political space in which individuals or associations of individuals are free to make decisions in the light of their deep personal or communal values. In the project we want to find out the extent to which there is agreement about the sorts of genetic and reproductive choices that belong in either public space or the space of individual liberty.

Third, both sorts of political space above are constrained by what I refer to as principles of just genetics/ just reproductive liberty. These constitutional principles form the outer boundaries of the space of rational democratic deliberation and forbid some genetic possibilities (technological possibilities or policy options). Some options may be chosen neither by individuals nor by the state. The intellectual task is to identify and articulate these constitutional principles. In the project we want to find out the extent to which such principles would be recognized and endorsed by participants.

Finally, we want to address the problem of non-ideal political practice. How can we protect deep moral and political ideals while working within the constraints of non-ideal political life? To what extent can we create dialogic processes that effectively realize rational democratic deliberation, i.e., yield real policy outcomes that are preferable to those achieved through "normal" political processes of raw majoritarian voting, interest group bargaining, legislative lobbying, media manipulation of public opinion, etc.? It is important to note that there are many mundane political problems that are appropriately left to the standard political processes. Rational democratic deliberation is appropriately invoked when our political problems involve controversial deep value issues.

In conclusion, it is too early to assess the success of the project as a whole. But I have been impressed by the quality of the dialogue, most especially the ability of individuals to express deep disagreement respectfully. If you wish to be part of this process, the Lansing area dialogues resume Monday, April 14, 7-9 p.m. in the Green Room of the Student Union and continue for six consecutive Mondays. Call Jan Holmes (355-7550) for reading materials.



## **Just Caring-Purchasing: Can the Market Produce Moral Outcomes?**

**by Andrew J. Hogan**

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The collapse of the Clinton Health Reform Plan 1994 has caused many health policy experts to conclude that there is no significant possibility of universal health insurance coverage in the U.S. for the foreseeable future. At the same time, disparities in access to health insurance continue to grow, if not accelerate.

Hopes for health system reform have now shifted to the private market. Many health policy experts consider that managed care and managed competition will develop a model for the efficient allocation of health system resources which the public health insurance programs can then adopt. Notwithstanding these hopeful signs, there is no evidence that the evolving private health care system is addressing any of the underlying moral issue of health care delivery. If anything, mechanisms that were in place to mitigate some problems of unequal access to health care are being undermined.

Those who are concerned about the moral dimensions of health care delivery now find themselves in the uncomfortable position of either continuing to advocate for a politically infeasible expansion of public coverage or defending the current unaffordable and inefficient health care delivery system. This essay proposes a third alternative: building moral outcomes into the evolving private health care market.

This new approach is called Just Caring-Purchasing and is an extension of the Just Caring approach to democratic decision making in health system reform proposed by Leonard Fleck (*MHR*, Winter 1996). It will require that the moral initiative shift from health professions and health care delivery system managers and their trustees to health care purchasers and ultimately consumers.

The essential feature of this approach is that the purchasers of health services demand from health care providers that the care they purchase produce moral outcomes, in addition to quality of care and acceptable cost. More specifically, health care providers would be required to compete for the business of health care consumers on the basis of price, quality and moral outcomes. Health care purchasers would choose health providers who could deliver services of equal quality and price with superior moral outcomes; purchasers might even consider choosing providers with modestly lower quality and/or higher prices if moral outcomes were sufficiently superior.

### **The Morality of Markets**

The social function of competitive economic markets is to produce the greatest possible material well-being as efficiently as possible. Consumers are assumed to pursue their own self interest with full knowledge of both the costs and benefits of what they buy.

A well-known shortcoming of this model is that the satisfaction enjoyed by one consumer is assumed to be independent of the satisfaction of other consumers. Empirically, it is recognized that the ability to enjoy material well-being is in some persons dependent on the ability of others to meet at least some basic needs -- parents find it difficult to enjoy a luxurious meal when their children are starving. The nature of this interdependency of satisfaction differs across cultures, social groups and income classes, but it is a widespread phenomenon that explains both private philanthropy and redistributive social programs.

Competitive economic markets are essentially amoral. A capitalist economy that permits child labor will tend to use child workers very efficiently. The fact that child labor became economically obsolete in some market economies does not prove that market economies produce moral outcomes. It is perfectly permissible in a market economy for consumers to insist that goods and services not be produced in morally reprehensible ways that will diminish the ability of the consumer to enjoy the good or service, e.g. dolphin-safe tuna fishing.

The key element in producing moral outcomes is for the consumer-purchaser to express a moral preference and to exercise that preference in choosing among products or services. A major practical issue is verification, especially when the moral outcome may involve a service delivered to another person.

## **Background**

Since 1994, the initiative for “reforming” the U.S. health delivery system has shifted from government to the private sector. At the forefront of private health system reform are managed care organizations on the supply side of the market and health care purchasing organizations on the demand side. While much attention has focused on ethical and distributive justice issues facing managed care organizations, little attention has been given to the ethical needs of health care purchasing organizations.

Commercialization of health care market provides the major justification for the need for Just Caring-Purchasing. Over the last decade private employers began to introduce purchasing techniques developed in the business world into the health care market. Combined with some high-profile, albeit half-hearted, efforts by the federal government to control health care inflation with a pro-competitive strategy, health care purchasing organizations began replacing the former communitarian market based on professionalism and altruism with one based on commercialization. The result is that values were once maintained by providers through professionalism must now become “outcomes” demanded by consumers.

Once these purchasing organizations mastered the technique of shifting patients from one provider to another, they were able to win significant price reductions from providers. These price reductions are not so much the result of greater provider efficiency as the avoidance of cost-shifting, which can easily represent 20-30% of the charge for a money-making service. In turn, providers have responded by reducing charity care and cross-subsidized services.

Now the conservative wave in both state and federal governments looks to the private sector for models to reduce public health insurance payments. Managed care programs are now being implemented for the politically weak Medicaid population, but are moving much more slowly for the politically powerful Medicare population.

With the commercialization of both the public and private sides of the health care market the old community-based mechanisms of health care redistribution are becoming non-functional. A new mechanism must be developed to instill community moral values into the health system. If left unattended, the commercialization of the health care market will pursue only two values, efficiency and quality (as perceived by the individual patient-consumer). Just Caring-Purchasing

is a mechanism to introduce a moral dimension into health care purchasing through the development of measurable moral outcomes.

### **Including Moral Values in Health Care Plan Outcome Measures**

In current practice, those who evaluate health plan or provider performance view outcome measures as merely the sum of the individual experiences of identically distributed patients. To incorporate moral values, we must reconsider these measures as representing the joint experience of interdependently distributed members of a coherent community. This will cause us to be interested not simply in the mean and variance of the outcomes measures, but also the distribution of the outcomes measures among groups of individuals. Most importantly, it recognizes the interdependencies of health plan/provider performance across groups within the community. The purchaser in this context is no longer the purchasing agent for a collection of independent, similarly insured individuals. The purchaser becomes a member of a community-based team whose joint purpose is to maintain or improve the health of the community as a whole.

The most effective approach would be to develop direct measures of moral values based on existing systems for reporting outcome measures. The Health Employer Data and Information Set (HEDIS) is the principal mechanism by which private purchasers are evaluating the quality of care provided by managed care programs. Using HEDIS as a framework, we will illustrate how moral outcomes can be included in standardized reports on health provider performance.

The categories for the measures used in the latest version of the HEDIS 3.0 Reporting and Testing Set are shown in figure 1. To expand the HEDIS measures to include moral outcomes, health purchasers could ask competing health plans to assess the community-wide impact of the services they deliver:

- Compare the racial/ethnic diversity of plan membership with that of the general community, and to undertake marketing efforts to correct any significant differences.
- Identify an unmet health care need in the community and to provide services to help meet that need.
- Open health screening programs to selected uninsured non-members.
- Assume responsibility for a fair share of the uncompensated care costs incurred by those hospitals from which they purchase services.
- Offer free or discounted enrollment to former enrollees who are undergoing economic hardship.

#### **Figure 1: HEDIS Categories**

- I. Effectiveness of Care
- II. Access to/Availability of Care
- III. Satisfaction with the Experience of Care
- IV. Health Plan Stability
- V. Use of Services
- VI. Cost of Care
- VII. Informed Health Care Choices
- VIII. Health Plan Descriptive Information

The crucial step is for health purchasers to reward health plans with superior performance on these moral outcomes measures with a larger share of the private insurance market.

### **A Possible Intervention**

To illustrate how the Just Caring-Purchasing approach might work with health care purchasing organizations, a possible intervention is proposed. Such an intervention might undertake the following process:

- 1) Educate the members of the health care purchasing organizations on the moral dimensions of health care purchasing.
- 2) Develop a consensus within each organization about the moral values the organization should pursue in purchasing health care.
- 3) Develop measures (moral outcomes) with which to operationalize the moral values developed in (2).
- 4) Negotiate collection of data on moral outcomes from health care providers.
- 5) Evaluate the performance of health care providers in terms of cost, quality and moral outcomes.
- 6) If necessary, negotiate new relationships with providers based on cost, quality, and moral outcomes.

Preliminary thinking is that Step 1 could be accomplished in three 3-and-a-half hour sessions covering general topics of health care economics, medical ethics, managed care, and outcomes research. The outcome of Step 1 is that each purchaser organization would have a list of health care purchasing issues with a significant moral dimension. Step 2 would attempt to develop a consensus on how to address the moral dimension of the previously designated health care purchasing issues. Step 2 could be accomplished in two to four 3-and-a-half hour sessions. In Step 3, the purchaser organization would begin to operationalize measures for moral outcomes, and would finish this process in negotiation with health care providers in Step 4. Steps 3 and 4 would be delegated to committees and the purchaser organization's staff, with perhaps one or two general meetings of two or three hours. Similarly, the initial work in the evaluation of health care provider performance would be done by staff and committee members, with one general meeting with the purchaser organization's membership. From Step 5 would come the recommendations for the possible renegotiation of contracts and relationships with providers. Step 6 would be carried out by the purchaser organization's staff.

When one considers that there are several hundred thousand businesses and other employers in a large state like Michigan, the process described above may seem implausibly large. However, market competition does not require that 100% of consumers be well informed. A seller of a service or product goes bankrupt long before they lose their last customer. Thus, it may only require that 10-15% of purchasers in some health care markets become morally conscious purchasers for the Just Caring-Purchasing approach to be widely disseminated; the remaining 85%-90% of the purchasers will become moral free-riders, who will over time come to expect moral outcomes as a normal feature of their health care purchasing.

### **Conclusions**

Just Caring Purchasing is a market-oriented approach for achieving moral goals through health care purchasing. Just Caring Purchasing would adopt and adapt currently evolving health care purchasing strategies to incorporate moral outcomes along with price and quality as major criteria for health plan and health care provider selection.



## Center News and Announcements

"Just Caring: The Moral and Economic Costs of APOE Genotyping for Alzheimer's Disease," by **Leonard Fleck** was published in the *Annals of the New York Academy of Sciences*, Vol. 802 Apolipoprotein Genotyping in Alzheimer's Disease (1996), 128-38.

**Leonard Fleck** was a co-author of the Consensus Statement "The Clinical Introduction of Genetic Testing for Alzheimer Disease: An Ethical Perspective," in *JAMA*, 277 (March 12, 1997), 832-36.

**Judith Andre** was elected to the Board of the Association of Practical and Professional Ethics. At the annual meeting in March she arranged and participated in a panel on faculty responsibility for university athletic programs, and presented "Professional Ethics as a Practice: the Case of Bioethics."

On March 27 **Leonard Fleck** presented "Just Caring: Managed Care, Health Care Rationing, and Capitation" to the Physician Assistant's program at Central Michigan University.

In March **Leonard Fleck** did a workshop for Leadership Detroit, Class XVIII, titled "Just Caring: Emerging Moral Challenges in a Changing Health Care System."

In March **Leonard Fleck** presented "Just Caring: Gatekeeping and the Ethical Challenges of Managed Care" to the staff of Providence Hospital in Farmington Hills.

**Tom Tomlinson** will present "Organ Donor Shortage: Ethical Dilemma or Moral Crisis" at the conference, Transplantation 1997: The Checks and Balances of Organ Donation, on April 25 in Dearborn, MI.

**Leonard Fleck** will chair two sessions at the American Philosophical Association meetings in Pittsburgh, April 24-27. He will chair "Recent Work on the Definition of Death" for the Committee on Philosophy and Medicine, and then the Ethical Problems Colloquium on "Medical Futility, Autonomy, and Golden Lies."

On May 2, **Tom Tomlinson** will present "The History of Modern Bioethics" at Butterworth Hospital in Grand Rapids, MI.

**Tom Tomlinson** will be one of the faculty at the Life Sciences Bioethics Institute, Michigan State University, May 13-17.

In May **Leonard Fleck** will speak at the annual meeting of the Association of Retarded Citizens of Michigan at Mackinac Island. His lecture is titled "Beyond the Age of Genetic Innocence: Ethics, Genetics, and Reproductive Decisionmaking."