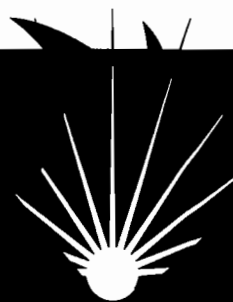


MEDICAL HUMANITIES REPORT



Spring 2001

Ethics, Genetics, and Community Dialogue: Lessons Learned

Leonard M. Fleck

For the past six years I have been a co-principal investigator for two NIH projects funded by a program of the Human Genome Project known as the Ethical, Legal, and Social Implications of the Human Genome Project (ELSI). The nest of issues connected with pre-implantation genetic diagnosis (PGD) is just one example of the kind of issues that were central to those two projects, ranging from the use of public funds for PGD, to the views of Disability Rights activists and of Right to Life activists. We also discussed a number of problems related to privacy and genetic testing, human cloning, human embryonic stem cell research, germline genetic engineering, social policy and genetic responsibility, and issues of justice related to funding new genetic technologies, among many other things. What was distinctive of both projects was that they were "community dialogue" projects aimed at engaging a good cross section of our population, as opposed to discussions that occurred among a bunch of academics or health professionals.

The Importance and Necessity of Addressing These Issues Through Community Dialogues

The issues that were the focus of our discussions were not merely academic or professional issues that could be appropriately resolved through those institutional channels. Rather, these were issues that would increasingly intrude into the lives of all of us at many points. Philip Kitcher, in his book *The Lives to Come: The Genetic Revolution and Human Possibilities*, put the point this

way: we have left the Age of Genetic Innocence; we have entered irrevocably the Age of Genetic Responsibility. He did not say that *some* scientists and doctors have left the age of genetic innocence; rather, the all-inclusive *we* have left that age behind.

As noted, our discussion issues potentially affected the lives of virtually all in our society; these issues pertained to very fundamental moral and political values, which is to suggest that these issues could not be resolved through expertise alone. In the PGD example introduced above, three core values at stake would seem to be the welfare of future possible children, fair treatment of those children, and the issue of invidious discrimination. As the number of possible genetic tests increases, there will be rapidly increasing demand for the tests, especially in connection with reproductive decisions.

Part of the reason for the failure of this privatizing strategy is that these "private" decisions have very significant social consequences that can

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only be managed through some sort of social response that is widely seen as reasonable and legitimate and somehow congruent with our deepest, most binding, most widely shared political values. Genetic tests, for example, are in many respects very different from other medical tests in that they often tell us much that is significant either for others or about others. There are others who might not want those things known by anyone else (children or siblings, for example). There might be others who would very much want to know that information because they would use it to alter fundamental life choices for themselves, i.e., reproductive plans. How should privacy rights, the significant welfare interests of others, and our sense of social responsibility be defined and adjusted in relation to one another in the context of genetic testing that may affect future possible children? This is not a question that can be satisfactorily answered by individuals as individuals, if adverse social consequences are to be minimized. We need a socially-fashioned response.

Finally, some philosophers may be tempted to think that the moral and political problems we addressed have clear, definite answers which philosophers can provide, using the resources of moral and political theory. But I would be prepared to argue that this is an excessively optimistic view of the resources of philosophy. The reality of our

moral and political life would seem to be this: When there are very specific conflicts regarding how we balance and respect genetic privacy, procreative liberty, genetic justice, and social responsibility (as with our PGD problem), there will usually be many morally permissible, politically legitimate, and reasonable enough choices that we might make. But the practical reality may be that “we” (some specific community) must make only one choice. A properly conducted rational democratic deliberative process, I argue, should be the primary mechanism through which we seek to fashion such choices.¹ The moral and political rationality of that process is what gives moral and political legitimacy to the result.

Important Defining Features of Community Dialogues

First, it is important to note that these community dialogues were not just “isolated gab sessions.” The phrase used to characterize these dialogues in academic circles today is “rational democratic deliberation.” Built into the phrase are the following working assumptions: (a) This needs to be a *rational* dialogic process, rooted in respectful reason-giving. As a society we must find a way of addressing the most controversial ethical and policy issues in our society without shouting, name-calling, and unthinking sloganeering, as we have

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seen regarding the abortion issue. (b) This dialogic process needs to be *on-going and cumulative, while engaging roughly the same group of individuals over a significant period of time*. We are talking about very complicated and very controversial issues that we cannot hope to resolve, or even adequately understand, in the space of a single two-hour public forum. Further, it is essential that social trust be established in the group, which requires that this conversation occur over a period of time. (c) This dialogic process needs to consider *a complex mix of related issues* in order to better appreciate that there are many relevant social values that will need to be compromised and balanced in relation to one another in order to fashion social responses or policy responses that are widely recognized as reasonable and legitimate by all who might be affected by them. (d) The dialogic process must be carried out in a *social problem-solving mode* as opposed to an adversarial mode. Put another way (in the spirit of John Dewey), even if in specific instances the dialogue process fails to come to any satisfactory social response, the process will have been successful if we increased through that process the store of social intelligence. What I have said so far may have something of an idealistic quality to it. But our goal in these two NIH projects was to test this approach to social problem solving in the real world. With that, let me briefly describe each project and how they were related to each other, then turn to a discussion of the key lessons we have learned so far.

The first project involved seven dialogue groups of thirty to fifty participants each in seven different Michigan cities. They met for a total of thirteen two-hour dialogue sessions clustered into two “semesters” in each community. In our recruitment effort we wanted to make certain we had a diversity of views going into the dialogues. So we made certain that representatives from Right to Life and disability advocacy groups and various church groups were in each group. We had a good age spread, and reasonable minority representation. But 80% of our participants had college degrees or better, hardly representative of most communities.

In assessing the first project we (the project investigators) wondered if minority groups, especially African Americans and Hispanics, had special concerns or distinctive perspectives to contribute to these dialogues. Though they were present in all the dialogue groups, there voices

would have been mostly washed out as distinctive voices. Hence, in the second project we sought participants from a broader socio-economic spectrum, and all fifteen groups were made up exclusively of either African Americans or Hispanics. We brought in Tuskegee University as a project partner with the University of Michigan and Michigan State University. We expanded our team of investigators so that roughly half represented minority groups. We engaged minority community organizations as partners in the project to help with the recruiting effort, and to participate in the design of project materials and in the creation of the project reports and recommendations.

In this second project, each dialogue group met for only five consecutive sessions, two hours each, and groups were much smaller (ten to twenty participants per group). We had to go with fewer sessions because our community partner organizations believed it would be impossible to recruit participants for a much longer project. We also had to adjust the topics that were the focus of the dialogue sessions. In the first project the investigators identified the issues that would be the focus of the dialogue sessions. These were all issues that in the past several years had received considerable media attention, so we did not feel that we were imposing “our favorite topics” on the group. That these topics resonated well with the group. Further, for the first session in each cluster of dialogues we were able to use a number of case scenarios that clearly engaged participants. That is, they saw these as problems worth discussion.

In the second project, we had to give each dialogue group more of an opportunity to “set the agenda.” We did that in two ways. First, we used a series of African American and Hispanic focus groups to identify about ten possible topics for the dialogue sessions. Next we allowed each dialogue group at its first meeting to pick three of those topics (or alternatives they might suggest) for the last two dialogue sessions. For the first three sessions we felt we needed common topics that would allow us to make comparison judgments among groups and with the earlier project. All of this required what is best described as negotiation, wherein academic researchers tried to convey what their “needs” were as researchers and community organizations tried to convey their “needs” as practical advocacy groups.

This was really our first “lesson learned”: negotiation is necessary and negotiation works. In

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this particular regard the difference in perspective could be described this way. These community organizations, accountable for their investment of time and resources right now, had to show practical results in the very short term. Issues that seemed “too academic” or “too remote” or “beyond amelioration” in a reasonable time period could not command their attention. Relative to issues of poverty, which was the mission of some of these agencies, our genetic questions were remote and academic. But we were able to show that these issues are of emerging relevance to minority communities, and this helped to facilitate buy-in to the project.

A second lesson learned from both projects was that dialogue works. Most of our citizens are capable of engaging in reasoned discussion with one another about morally and politically controversial topics. In none of our dialogue sessions did we have anything approaching the mindless verbal warfare that is often associated with abortion

discussions. The key to achieving this result was the ability of project investigators and dialogue facilitators to create in the minds of each participant a state of internal moral conflict regarding each issue we

took up. That put everyone in a “group problem solving” frame of mind, as opposed to an adversarial frame of mind where the objective is to score points for one’s interest group or ideological brethren.

Reasoned agreement did emerge from the dialogue process regarding a broad range of genetically related moral and policy judgments. We are not saying that we achieved unanimity on any issue, but that participants’ views on these matters developed and became more nuanced through this process.

A third lesson learned from these dialogue projects is that there are distinctive concerns and perspectives regarding these genetic and reproductive issues in the African American and Hispanic communities. Space does not permit a long cataloging of those distinctions (to be presented in future project papers and reports), but a few examples might be helpful.

(1) A major theme in the African American and Hispanic dialogues was trust/distrust. This is a

point that was virtually non-existent in the first dialogue project. The distrust extended to government, to researchers, to health care institutions, to businesses, each case being differently motivated. The memory of Tuskegee was invoked with some frequency. That explains some of the distrust of researchers. In the case of government, the distrust was connected to ineptness and fear that powerful special interests shaped government to the disadvantage of those less powerful in our society. Businesses were distrusted because it was feared there were no moral norms that constrained business behavior when profits were at stake. This often led to the conclusion that government had to be involved in overseeing and funding genetic research so that there was public accountability from the private sector.

(2) There was an interesting response to the distrust problem that developed in the dialogue groups. Few thought that African Americans or Hispanics ought to divorce themselves entirely from

genetic research. Rather, the emphasis was on encouraging their children to pursue careers in science, to become part of that research enterprise in order to be in a position to shape it humanely. The emphasis was on minority

entrepreneurs involving themselves in this research, or pursuing roles in government where policy could be formulated to shape the direction of the research.

(3) One interesting perspective that emerged in this second project was in relation to eugenics, or the “perfect children” problem. In both projects strong reservations were expressed about the re-emergence of eugenics. But in the second project the concern was that “perfect children” would be defined in reference to dominant cultural traits, which would result in a devaluing of traits associated with minority groups. This is not something that would come about as a result of any coercive government policy. It could easily come about through millions of free unforced decisions by potential parents. The consequences in either case would be just as worrisome.

To conclude, there is one major challenge regarding such community dialogues with which we are still struggling. In brief, a goal of the dialogue

(continued on p. 6)

Participants' views on these matters developed and became more nuanced through this process.



InkLinks

Reflections on Genetic Science and Minority Voices from Readers of the Medical Humanities Report

InkLinks is a regular column for readers' response. This month readers respond to the lead article in this issue: Len Fleck's description of seeking minority group input about the implications of genetic science. If you would like to carry on this conversation, or start another, please drop us a line.

—JA

The Role of Stories

Professor Fleck took a number of steps to try to include minorities in the community dialogues he conducted. Other steps have been proposed as well; some, for instance, suggest allowing and encouraging people to tell stories to get their points across. For many people this is a natural and culturally expected means of communicating, and stories have certain advantages: we all know how to tell them, and we can judge when a story is good or bad. While I support the general idea of accepting narrative in these arenas, I want to suggest that we not expect too much from it. However many stories are brought to the dialogue, it is possible that differing opinions may still go unheard; people bring in preconceived ideas that shape the way they hear what others say, even or especially when what is said is in the shape of a story. Whether or not we advocate narrative, we should pay serious attention to how to get people to hear one another. Unless different ways of making a point can be understood, community dialogues will remain too narrow.

Allison B. Wolf
Graduate Student, Philosophy

The Role of Poverty

One of the challenges associated with the extraordinary advances in genetic science is the inclusion of those who generally have no voice in policy development: minorities, low-income families, and disabled individuals. Another challenge is insuring that minorities can utilize genetic science advancements, when existing health care systems are neither accessible nor affordable. In his essay in this issue of *MHR* Len Fleck states that access to technologies such as pre-implantation genetic

diagnosis will likely "be determined by the ability to pay . . . [As a result] children in less well-off families would continue to be born with these disorders." Molly A. Lauck has shown the kind of strategies that low-income Mexican American women now use to gain access to medical care: they get information from friends, borrow a parent's car, trade shifts with coworkers, get a sister to fill out an application. These women are highly resourceful. Yet if we continue to leave the poor to devise their own strategies for access, the benefits of the new genetic science will elude too many.

Julie Reyes
Graduate Student, Anthropology

References cited

Lauck, Molly A. 2000. Disparities in Gaining Access to Prenatal Care: Low-Income Mexican American Women's Social Resource Management. Dissertation submitted to Michigan State University.

The Concept of Race

Westerners typically classify persons of Asian descent as representatives of a distinct race. On the other hand, members of various subsets within this said classification (the Japanese, Koreans, Chinese, Vietnamese, etc.) tend to view one another as separate races. Perhaps with our ever-increasing knowledge of the astonishing similarities all human beings share genetically, we will rightfully come to view race as an arbitrary (and potentially pernicious) way to categorize persons.

Insoo Hyun
Western Michigan University

(continued on p. 6)

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(Inklings, from p.4)

The Fact of Mistrust

My mother would never take a flu shot. Every year I would suggest that she get a shot and every year she would refuse. Finally, I asked her why she was so reluctant. She said quite emphatically that she did not trust the government and she would never take anything they wanted everyone to take. While my mother does not speak for the majority of blacks in the United States, she was expressing a common sentiment.

Almost every day we awake to some extraordinary success in genetic science, usually thought to be an advance for humankind. However, my mother came of age during a period that was marked by legalized discrimination and segregation. She never forgot the lessons she learned. Scholars,

scientists, and medical professionals often work within an isolated world, a world of good people with honorable intentions. People like my mother live in a different world. They realize that all too often neither science, scientists, nor the government have been their friend. Too much science research has been used to show that minorities and women are different, and the differences are not positive. Often it was thought important to control or eliminate the differences, for the good of humankind and, of course, the good of the targeted group itself.

When I hear the daily news reports of breakthroughs in genetic science, I can hear my mother's words: "Don't trust the government." I can only hope she was wrong.

*Bill E. Lawson
Department of Philosophy*

(Fleck, from p.4)

process was to contribute to the shaping of better public and professional policies for managing the social problems that are connected to these emerging genetic and reproductive technologies. But the achievement of this goal requires solid linkages between these dialogues and the more formal policymaking processes in our society. The pitfall to be avoided is having these dialogue groups and

their judgments diminished by being regarded as "just another interest group" competing for control of the policy agenda and policy outcomes.

*Leonard M. Fleck,
Michigan State University*

Notes:

1-- See: Fleck, Leonard M., "Just Health Care Rationing: A Democratic Decisionmaking Approach" in *University of Pennsylvania Law Review*, 140 (5), May 1992, 1597-1636.

11th Annual Conference: Medical Ethics for the Twenty-first Century

June 27-30, 2001

**Kellogg Center, Michigan State University
East Lansing, Michigan**

This program is intended to be an intensive basic course in medical ethics. Participants are assumed to be formally or informally connected to institutional ethics committees. It is also assumed that participants wish to be more knowledgeable and effective members of those committees, and that they will likely have a role in shaping ethics education programs within their institutions and their communities. The program is designed to introduce participants to all of the standard topics in clinical medical ethics with which members of a hospital ethics committee should be acquainted.

In addition to the standard topics in clinical medical ethics, a second focal point for this course

will be issues of justice and resource allocation. The pressures for health care cost containment that emerged in the 1980s will only grow more intense in years beyond 2000. Further, since the 1990s, genetics and new reproductive options have become more prominent parts of medicine.

Mary Briody Mahowald, Ph.D., (Univ. Chicago) will deliver the keynote address entitled "Reproduction and Genetic Testing: Ethical and Policy Issues."

To have registration information mailed to you, contact the Office of Continuing Medical Education, College of Human Medicine, MSU at 517/353-4876 or via email at chmcme@msu.edu.

Center News & Announcements

The *MHR* congratulates Judith Andre, who has been awarded the Outstanding University Woman Faculty Award by the Faculty-Professional Women's Association of MSU. This award recognizes Andre's excellence in teaching, research, and service, and her support of the goals of academic-professional women.

Clayton Thomason presented a lecture entitled "The Dilemmas of Dahlia Davis: Competency and Consent Issues," at the 10th Annual AGES Geriatric Conference, Saginaw Cooperative Hospitals, Inc., Saginaw, MI April 6, 2001.

Libby Bogdan-Lovis moderated a panel discussion "A Comparison of U.S. Midwifery and Traditional Birthing Practices in Zimbabwe" as part of the College of Human Medicine's "Global Women's Health Week" activities.

Len Fleck served as chair for the Philosophy and Medicine program at the Pacific Division meeting of the American Philosophical Association. The session was a critical assessment of *From Chance to Choice: Genetics and Justice* by Allen Buchanan, Norman Daniels, Dan Brock, and Dan Wikler. The title of Fleck's critical commentary was "Health Care Justice and Genetics: Four Unsolved Problems."

Howard Brody gave a keynote address at the South Carolina Healthcare Ethics Network, where he spoke on ethics committees and access to care, March 30, 2001.

Tom Tomlinson's essay "Telethics and the Virtual Intensivist," will appear in the upcoming issue of *Journal of Clinical Ethics*, 12 (Spring) 2001:69-72 (forthcoming).

Judith Andre, Jake Foglio, and Howard Brody wrote "Moral Growth, Spirituality, and Activism: The Humanities in Medical Education," featured in *Educating for Professionalism: Creating a Culture of Humanism in Medical Education*, Delese Wear and Janet Bickel, eds.. (Iowa City: University of Iowa Press 2000) 81-94.

Len Fleck did a critical essay titled "Healthcare Justice and Rational Democratic Deliberation" *American Journal of Bioethics*, 1 (Spring 2001), 19-21.

Clayton Thomason presented a series of three lectures on the theme of "Spirituality and the Practicing Physician," for the Residency Psychosocial Rotation, Department of Medicine, MSU College of Human Medicine March 19 through April 4, 2001.

2001 MERN Annual Meeting

The Michigan Ethics Resource Network (MERN) will hold its 2001 Annual Meeting Friday, May 11, 2001. The title of this year's conference is "Brave New World: Intersection of Bioethics, Law, Spirituality and Reproduction." Dan Brock, serving as keynote speaker, will present "Reproductive Freedom and the Prevention of Genetically Transmitted Harms."

Among the various papers that will be presented are "Ethical Issues in the Delivery Room"; "How to say What Needs to be Said – End-of-life Communication"; "Manipulation of Reimbursement Rules for the Patient's Benefit." There will also be a panel discussion / plenary focusing on "Spiritual and Legal Perspectives in Reproduction."

The conference will be held at the Weber's Inn, Ann Arbor, Michigan. For further details on the conference program and registration, please visit our web site at <http://www.bioethics.msu.edu/>, or contact Jan Holmes at 517-355-7550.

As an organization, MERN seeks to promote a closer collaboration between members who work in hospital or other health care settings and those who work in academic settings.



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Coming Events

**The Center for Ethics and Humanities
Spring 2001 Brown Bag Series
C-102 East Fee Hall**

Medical Decision-making at the End of Life in a Japanese Context

May 10, 2001 4:00 PM — Tomoko Teraoka, M.D.

Western medical ethics gives priority to patients' autonomy in the decision-making process. What autonomy means, however, varies depending on the patient's personal life values or the prevailing cultural values of the environment in which he or she lives. In the Japanese culture, dependency and harmonious relationships with close others play an important role in making medical decisions. Information disclosure that is usually justified by the concept of patient autonomy, the core principle of modern medical ethics, may fall short of the needs of some moral traditions. This presentation emphasizes the importance of a physician's duty as a messenger between a dying patient and his loved ones by facilitating closer communications.

Tomoko Teraoka received her M.D. from Osaka Medical College in Japan. Her research focuses on informed consent and medical decision-making at the end of life in a Japanese context. She received her MA in Bioethics from the Medical College of Wisconsin, and is currently a fellow at the Center for the Study of Bioethics at the Medical College of Wisconsin.

For more information, please visit the Center's website at <http://www.bioethics.msu.edu/>.