

Keynote Address

What Sort of Nation Shall We Be? : Genetics, Reproduction, and Shared Values

May 15, 1998

8:45 - 10:00 AM

Introduction: Leonard Fleck, PhD

Keynote Speaker: Thomas Murray, PhD, Director, Center for Biomedical Ethics, Professor of Biomedical Ethics, Case Western Reserve University

I am going to begin with just a few reasons for why we're here, and why this project. The first couple of reasons I will borrow from the philosopher, historian and political theorist Michael Walzer, and a book he's written called *Thick and Thin: Moral Argument Home and Abroad*. Walzer opens the book by recalling a scene in 1989 watching television and seeing demonstrators in Prague, Czechoslovakia carrying signs. The signs are simple—some read “Truth;” some read “Justice.” Walzer's discussion of these signs and demonstrations is an effort to understand how it is that people in Prague, Czechoslovakia, who as of 1989 had a political tradition quite at odds with our own, could hold these principles in this way. He is also interested in how we could understand what they were talking about. How is it that someone who has lived a lifetime under Communism could demonstrate for truth and justice, and yet we, at some level, know what they mean? What is it about the values truth and justice that we share with people whose political experience is so different from ours? The second example Walzer uses is Tiananmen Square. Remember Tiananmen? Do you remember Lady Liberty? No signs there, at least not in English that I can recall, but they made their own version of the statue of liberty, and it clearly meant a great deal to them. At the same time it was something that we think we understand, at least in part. Their demand for liberty, their demand for the values that symbol meant to them are also, Walzer would argue, at least in significant measure values that we acknowledge and share with them, recognizing them as our own. How is that possible?

Across cultures, certain shared values may be more difficult to articulate. And the understandings of those values might differ among cultures. For example, the Chinese demonstrators' understandings of liberty in China might be more Confucian than American. But still, there was something about their concern for liberty, something about the Prague demonstrators' passion for truth and justice that we can acknowledge and understand that we share.

Let me give you two other quick examples. A woman comes to her physician. She is a descendant of people who lived in the shtetls of Eastern Europe. She's an Ashkenazi Jew. She's read about the risk of breast cancer related to particular mutations in the two breast cancer genes BRCA1 and BRCA2 for people who share her ethnic heritage, and she'd like to be tested for them. She is tested, and she turns out to be one of the roughly two percent of women from that ethnic background who have one of the three known mutations in these two different genes, and she's concerned. She's concerned about her privacy, and she's concerned that if certain organizations find out about this, for example, her health insurer, that she may lose access to health care. The second example is one that I discovered while reading a book on cloning written by *New York Times* science writer Gina Kolata. Kolata relates this example near the end of the book. Suppose we could actually do somatic cell nuclear transfer cloning—the technical name for what they did with Dolly the sheep. Suppose we could do it with

humans. Here's the idea. Consider a woman with no viable eggs of her own. Her reproductive system is otherwise intact, but she has no ovaries. We take one of her cells along with another woman's egg. We rip the nucleus out of the latter's egg and replace it with the nucleus from the first woman's cell. Then we implant in her the egg which contains her genes, not the genes of the woman who provided the egg. She becomes pregnant with a fetus genetically identical to herself. When the fetus reaches the right age, we abort the fetus, take its ovaries, and pull out the eggs. We then cultivate these eggs until they are mature, and now the woman can have a child with, in effect, an egg genetically identical to her own. We've used her fetus to grow her a new set of ovaries in effect, and to harvest its eggs. Does that scenario make anybody a little queasy? If, as I suspect and hope, it does, then we need to talk about the shared values that underlie our reactions to that scenario as well as to the other cases we've mentioned.

Michael Walzer argues that what we shared with the demonstrators in Prague, their passion for truth and justice, was, in an important sense, thin. We shared enough of a common understanding of truth and justice with those demonstrators to evoke our sympathies, and to provoke our outrage. All that was required was a sense that it is wrong to be lied to, especially by those in power; it is wrong to be treated unfairly. Calling such shared understandings across cultures "thin" is not meant in any way to minimize their importance. But it does signal that there is a great deal of work, an enormous amount of conversation necessary, to work out the much more detailed and specific shared understandings vital to those who share the same general cultural and political community—those shared understandings Walzer calls "thick." We need to articulate the values that we share with our fellow Americans as thickly as we can if we are to have any hope of dealing with advances in genetics and in reproductive technologies. Our public policies ought to reflect the best and most widely shared values among us. How should we think about this quest to identify these shared values?

I fear that many people, certainly in America, are inclined to focus on the most intractable and violent moral conflicts as being the prototypes of moral disagreement. The "A" word immediately comes to mind - abortion. I suspect that many people think that the argument over the ethics of abortion is typical of all moral disputes—virulent, stubborn disagreement, especially over what are seen as "first principles," such as the moral status of fetuses. I believe that abortion is an atypical and unfortunate example. Many moral disagreements are much more open to genuine dialogue, persuasion, and compromise. Let me suggest a different kind of metaphor for thinking about moral disagreement and moral agreement. As a scholar in bioethics, I tend not to publish articles, not even to try to publish articles that say things like "Telling rotten lies for no good reason is wrong." I don't know a respectable journal that would print such an article. Journals are not interested in such manuscripts, not because they are wrong, but because they are uninteresting. Of course, it's wrong to tell lies, especially toxic lies, without any good reason! Scholars are not supposed to repeat the obvious. They are expected to focus on new things, matters that are controversial, unsettled, where the values or the principles are difficult to sort out. Those are the questions on which we focus our attention. The other stuff is obvious.

Think of an iceberg, and think of the ten percent above the water that we can see as the kind of moral conflicts that are visible to us. Imagine that this visible portion of the iceberg contains the visible areas of moral disagreement. Think of the remainder of the iceberg, the ninety percent that's under water, as our shared values, as all those things about which we pretty much agree. If we did not have the ninety percent, we couldn't talk in any meaningful way about the ten percent. If we didn't have a deep and

broad foundation of moral agreement, there would be no way to address the moral disagreements above the water. Moral disagreement makes the effort to find shared values necessary. Moral agreement, the part of the iceberg that's not visible, makes that effort possible.

Science and technology in areas like genetics and reproductive technologies are challenging us to be extremely clear about what we value. Questions that we've been able to not think about very much are now being pressed upon us. In a way, these questions ask us, "What sort of nation, what sort of people and communities shall we be?" I have a bit of a thesis that I'm going to pursue for the rest of what I say this morning. The thesis is a very straightforward one: that with genetics, we are having a kind of national dialogue, however fractured, fitful, and occasionally misinformed. Nevertheless, it's a national dialogue that gives us some hope that our shared values can be identified and articulated, and that those values can influence, if not fully determine our public policies. On the other hand, with assisted reproductive technologies, despite the technologies and their implications being, I think, more familiar to us, my fear is that our national conversation about shared values has been short-circuited.

I want to talk very broadly about two efforts. They weren't community dialogues of the sort that Toby Citrin and Len Fleck are going to be describing later, but they were efforts to get some sense of community belief, sentiment, and values. The first took place in the early part of this decade with the Ethical, Legal, and Social Issues Working Group for the Human Genome Project. The second is going on right now with the National Bioethics Advisory Commission. Let me begin with the experience earlier this decade. The Human Genome Project is an international scientific effort to map and sequence all human DNA within about fifteen years. In the late 1980's, the Human Genome Project was the subject of Congressional hearings to consider whether to have such a project. At one of those hearings I made the suggestion, which I'm sure quite a few other people were making at about the same time, that we might just try something different. Why not attempt to anticipate the ethical, legal, and social issues, rather than wait until they collapsed upon us? I've sometimes thought of the role of the bioethicist as the man or woman who follows the elephant in the circus parade. Every time the elephant makes a mess, we go in with our shovels and try to clean it up. In the genome project, we've been permitted to walk alongside the elephant. It's still an elephant. It still receives 95 to 97% of the funding, which I think is appropriate, but we are allowed to try to nudge the elephant, to lead it away from destructive directions.

At that time, much of the concern was what would happen if we could predict who was going to become ill because of a person's having some genetic predisposition. That's probably not news to you today. It was not so well understood in the late 1980's. The ELSI Working Group began its work around 1990, and rapidly came to see that genetic discrimination was a crucial concern for many people. I became convinced that it was a realistic concern, although more so in the near future than immediately. We did not anticipate a flood of genetic tests by 1990 or 1991, but we thought that the concern about genetic discrimination, especially in insurance, was reasonable given what we knew about the development of test technology, and about how the insurance industry works. We thought it was worth pursuing, and we formed a task force on genetic information and insurance. The task force quickly focused on health insurance. The two most important reasons were that people cared most passionately about health insurance, and secondly, that health insurance works somewhat differently from other kinds of insurance. With other forms of insurance, if I have information that suggests I am especially likely to file a claim, my withholding that information from my insurer could actually be much more catastrophic. Imagine, for example, that you bought a disability income policy at age 25,

knowing that you are likely to be disabled within two years. I don't know any genetic test that would give you that information, but let's say there was one. I'd pay very low premiums for the two years I was paying premiums, and the company would have to pay out for me for almost four decades. The financial risk to the company is actually quite enormous. Health insurance is different. The big payouts are a much smaller percentage of the business. The underwriting nature of health insurance is different from the financial risks to companies in disability income insurance. So, we focused on health insurance.

We gathered a variety of groups, including insurance company representatives, as well as people representing individuals and groups with genetic disease or at genetic risk, and a handful of experts. We found a number of disagreements. One I'm going to talk about a little bit later is whether there is anything special about genetics, or whether genetic information really is like other kinds of information about us. But the other interesting disagreement we had was about fairness. What's fair? Now, my own theory, which I confess I only have anecdotal evidence for, is that arguments about fairness or justice are the very first arguments people engage in. If any of you have more than one child, you have had debates about justice in your household. They probably run something like debates I remember when my children were quite young. We would let Kate, the oldest, stay up later than her sister Nicky, because Nicky at that point was only about four, and Nicky would say, "But why does Kate get to stay up later?," and we'd say, "Well, she's older." "That's not fair," Nicky would say. "She doesn't need as much sleep as you do," I would explain patiently. "I don't need any sleep, it's not fair," Nicky would answer. In my experience these debates about justice and ethics quickly turned into displays of sheer political power when eventually I said, "Go to bed, because I'm the parent!" So fairness is very important, and it was surprising to us to learn that there were people out there who actually had different ideas about what's fair. But in fact they do. Insurers have a concept of fairness they bring to thinking about issues like "To whom do you sell policies? At what rates?" The concept goes by the technical name of "actuarial fairness." Actuarial fairness dictates that you pay according to your risks. If an insurer ignores information about you, information that indicates you have a higher risk than someone else, actuarial fairness says this would be unfair. Specifically, it is unjust to the other person, the individual with lower risks who is, in effect, paying for your risks as well as his or her own.

In another context, business insurance, for example, actuarial fairness may seem quite sensible. Consider two hypothetical employers. One owns a factory, keeps oil-soaked rags lying about, and encourages her workers to smoke and throw the butts in the corner. The second employer has the cleanest, most fireproof facility in the world. If an insurer charged them the same rates for fire insurance coverage, the person with the clean factory would protest, and I frankly think they'd be right to protest. The person with the firetrap factory would be thrilled to be charged the same rate as the other employer, but that seems blatantly unfair. That's actuarial fairness. You pay according to your risks of a claim. It seems like a sensible position to hold about fairness, if certain other conditions are satisfied. For example, to the extent that the risks are at least quasi-voluntary, that makes a difference. The first employer had a choice whether to have oil-soaked rags around her plant. A second important factor that seems to distinguish business insurance from health insurance is the answer to the question "What am I paying to protect?" In the business example, the employer is basically paying money to protect money. Money for money seems like a fair trade. The problem for at least some members of the task force (actually for all the members of the task force except for the insurance members) was that extending the logic of actuarial fairness to health care makes it crystal clear that health insurance,

when its availability is contingent on individual risks, is quite simply a Catch 22. Most people know what you mean by the phrase “Catch 22”; quite a few people have seen the movie; very few have read the novel, I suspect. The insurer least wants to cover you against the disease that you’re most likely to have. That’s why they have these various exclusionary clauses in some contracts. That’s why they can choose to not cover you at all if they think you’re going to be an overly expensive case.

Insurers may reply that most people don’t experience any risk rating, what’s called “underwriting” in the profession. If you belong to a large group, insurers don’t bother to look at individuals’ risks. It’s not cost effective to investigate individual risks for two reasons. One is the law of large numbers, a law unlikely to be repealed in the near future. The law of large numbers says that, in the context of insurance underwriting, events with low probabilities—such as severe, costly illnesses—are unlikely to occur disproportionately often if the population is large enough. The second factor is the so-called “healthy worker” effect. Populations of workers and their families are actually healthier on average than individuals or families where no one works. Insurers know that, and that’s why they prefer to go after populations of employees rather than to just have a community pool which would contain many families in which no one works. There is, on average, less illness in families of people who work.

If you get your health insurance by virtue of working for a large employer, you will likely escape any individual risk underwriting. Many people, however, work for a small employer—small, by the way, could be a hundred employees. Most jobs in the American economy are created by small employers. Companies with as many as a hundred employees may be considered “small employers” for which all employees’ risks might be investigated. Furthermore, even larger plans get a kind of indirect underwriting if their costs go up in certain categories. Insurers can raise the rates charged to an employer if, for example, even a few employees or family members became seriously—and expensively ill. There was a case a few years ago in Texas involving the H & H Music Company, which was insured through a commercial company. They had an employee infected with HIV. Under the company’s health insurance policy they were having to pay for his care up to the maximum lifetime cap which, as I recall, was a million dollars. H & H Music Company then became a self-insured company, which is permitted under a federal law, the Employee Retirement Income and Security Act (ERISA). By becoming self-insured, H & H Music effectively exempted itself from almost all state regulation. There’s another Catch-22 here, by the way. ERISA, which is a federal law, says that companies that self-insure are exempt from most state regulation of their insurance programs. A different federal law says that the federal government may not regulate insurance, and must instead leave that to the state. So, if you self-insure, ERISA forces the state to keep its hands off, and the federal government is kept at a distance by yet another law. Regulation of the insurance programs of self-insured companies, not surprisingly, is minimal. H & H Music’s new health insurance policy continued to cover AIDS, except that rather than the one million dollar lifetime cap for all other diseases, the lifetime cap for AIDS was now five thousand dollars. The case was appealed, and the company’s actions were upheld. I understand that there have been some legal reforms that would prohibit such a maneuver today. H & H Music, however, was merely following the logic of insurance underwriting. It’s Catch 22; “as a company, we don’t want to be paying for the illnesses that might be expensive and that your employees are most likely to develop.”

That’s one notion of fairness - actuarial fairness. This is a case where dialogue about shared values would be terribly important. My sense is, judging from a variety of lines of evidence, that most people think that when we’re ill we ought to have coverage. Contrary to the Catch-22 now present in

commercial health insurance, many Americans seem to believe that where we are most likely to be ill is where we should be most assured of coverage. It's the precise opposite of actuarial fairness. Now the interesting thing is, even the members of the task force agreed with that, including the insurance members. They just didn't want to have to cover you if you are likely to be ill. In the later stages of the Task Force's work, I recall thinking that the dialogue seemed occasionally as if it had been plucked from the theater of the absurd, perhaps Eugene Ionesco's play *The Bald Soprano*. I recall a conversation in which the Task Force members who did not come from the world of insurance would ask a question like: "Do you think that everyone ought to have access to health care when they need it?" and the insurance representatives said, "Yes." The non-insurers would then say, "Ah, universal access!" The insurers would say emphatically, "No." Eventually, we discovered that to insurers universal access means roughly this: as long as I'm healthy, I don't pay a penny in premiums; the day I get sick, if I take a check to my insurer, they must accept me in their plan. The rest of the group responded that this was not what they meant by universal access. The insurance representative said that this is what "universal access" means in his industry. So we chose a new term, "universal participation," meaning that everyone must participate in the funding of health insurance all along, and that it would be there when you needed it. The insurance representatives seemed content with that, at least until their organizations had to officially sign on to the report. Our analysis and recommendations were published under the title *Genetic Information and Health Insurance*. I believe the report is still available through the National Institutes of Health. We made a number of recommendations, but essentially we concluded that there should be no underwriting in health care coverage. That is, your ability to get coverage, or how much you pay, or what's covered, ought not to be affected by existing disease or by risk of disease. What matters is that the coverage be there for you in an appropriate way when you genuinely need it. In the end, the national Blue Cross / Blue Shield organization signed onto that report. The Health Insurance Association of America did not sign it in the end, nor did they oppose it. They just issued a statement that said, "There are some things about it we like; some things we don't like." The only group to actually oppose it was the American Council of Life Insurers, which was quite interesting because we devoted an entire appendix to say that this report is not about life insurance.

One of the toughest challenges we faced in the Task Force was figuring out whether genetic information was like other kinds of information. Many people have said that genetic information is different, even unique. Colleagues at Boston University, for whom I have the greatest respect, have very skillfully drafted a model Genetic Privacy Act. Nevertheless, I disagree with their strategy. First of all, the state laws, particularly the discrimination laws, are, by and large, feckless. The definitions tend to be exceedingly narrow. They are typically defined as the results of a direct DNA test. In fact, most of the genetic information insurers receive about us will not be direct DNA test results. Such tests are less interesting than what comes downstream from the gene - the so-called "gene product" and its effects. We're really interested in, for example, whether the gene makes enough of an active form of an essential protein. So, if I develop a test for the protein the gene's supposed to make to see if it's there in a normal quantity and normal form, these laws have nothing to say about that. Given the way many of these laws are written, only if the insurer bases its decision on the DNA sequence does it violate the law. In actual practice, I fear that such laws will be effectively useless.

The typical state genetic privacy and discrimination laws protect a very small number of people. The model Genetic Privacy Act itself adopts a very narrow definition of genetic information, and the authors of the model act are very clear about this. They recognized clearly their problem: either take a

very narrow definition of what's genetic information, or adopt a broader definition. If the latter course is chosen it becomes difficult, perhaps impossible, to distinguish genetic information from all other kinds of medical information. I agree with that. Unless we adopt an exceedingly narrow definition of genetic information—one that leaves out a great deal of what we would normally count as that—we end up being unable to carve off genetics from other sorts of health-related information. George Annas and his colleagues, in a defense of the Genetic Privacy Act, refer to our genome, our DNA as a coded, probabilistic, future diary. Keep that image in mind: a coded, probabilistic future diary. They go on to say one's genome describes an important part of one's future. They describe it as being in code and largely unknown to the person. And, they warn that parts are being deciphered almost daily.

As I looked at the writings of people who argued in favor of genetics being different from other kinds of information, I found three major kinds of arguments. I'm going to call them: genetic prophecy, the concern for kin, and the concern about genetic information. Genetic prophecy, very simply, is the notion that I can find out something about you today that might indicate your risk of disease in the distant future. I can test a newborn to see if they have the gene for Huntington's Disease, a disease unlikely to manifest even its first symptoms for forty or fifty years. Huntington's Disease turns out to be the exception rather than the rule when it comes to the predictive accuracy of genetic testing. Most genetic tests for most diseases are not going to have this simple causal connection. It will not simply be the case that if you have the gene, you're going to get the disease. Take the example of a woman being tested to see if she has a mutated BRCA1 gene. If she doesn't have a mutation in the gene, her risk of breast cancer is still the population risk. That is to say, knowing nothing about a woman's genes, her lifetime risk of breast cancer is 11-12%. If she has a clinically significant mutation in one of the breast cancer genes, her lifetime risk, initially thought to be as high as approximately 85%, is according to more recent estimates closer to 50%. Such a four- or five-fold increase over the background rate may be reason for concern, but it's not a death sentence. And in fact, most of the cases of breast cancer occur in the very last decades of life—60's, 70's, 80's and beyond. So, is genetic information different from other health-related information? The results of a cholesterol test are information about one's future risk of heart disease. Living in a badly polluted part of the city might also be information about your future risk of disease. Living in Denver, where there is less protection from ultraviolet rays, may increase one's risk of skin cancer. There are many non-genetic factors that also seem to have some of the same prophetic qualities as genetic information. Except for these relatively rare relationships like Huntington's, where there is a virtual one-to-one correspondence between mutation and disease, most of these disorders are probabilistically linked to their diseases. The fact then that genes are occasionally prophetic doesn't distinguish them from many other things.

What about the concern for kin? The argument here is that if I get a result from your genetic test, I'm also learning something about your biological relatives. This is true. Genetic information about an individual may indeed be information of a sort about that individual's biological relations. Of course, so would information that one member of a family has been exposed to an infectious disease, or that certain family members may be physically or psychologically harming other family members. So the concern for kin is not unique to genetic information.

The third kind of argument is over concern about genetic information. Certainly, genetic information is not the only sensitive information about us that we want to protect from the prying eyes and instruments of other people. This last argument must rest, in some sense, on the claim that genetic information is especially sensitive.

Let us return to the metaphor of the coded, probabilistic, future diary. The genetic diary, after all, was written not only by others, but without our permission or necessarily even our knowledge. In the early days of the genome project, I had gone to a seemingly endless round of conferences in which people seemed to be saying similar things. At one of these events, I had lost interest in the presentation and received a tap on my shoulder from a very interesting friend I had come to know, the head of the FBI laboratories. I leaned back, and he said that they had finished the testing on the World Trade Center bombing samples. A letter had been sent claiming credit. From the back of the stamp, they identified one of the suspects. You leave enough DNA when you lick a stamp to do a DNA fingerprint. He said that they had also tested the envelope flap and a different person licked that, not one of the current suspects. I then had an epiphany: what I thought at the time was the world's largest collection of identifiable genetic samples was held by Publisher's Clearinghouse. We even put on our own return address! I'm still not sure whether they've ever realized what a treasure-trove they have. The point is that it isn't difficult to get genetic information about us if somebody really wants to. It's still expensive, and there isn't that much information we can get right now from such samples. But, we can understand why we'd want to prevent strangers from getting that information about us, if we really don't want them to know.

How does the metaphor of genetics as a "future diary" mislead us? First, it implies that the contents of this future diary, our genes, reflect what is most intimate, central, and important about us—that it reveals in some fundamental way our social and personal identity, our loves and interests, what we care about most deeply. In fact, our genomes have little or nothing to say about any of these crucial matters, despite the claim for a gene linked to IQ. The metaphor also promotes something which philosophers call genetic determinism; a doctrine that somehow our genes literally determine important outcomes for us. In fact, in complex disorders with many contributing factors, such as cancers, heart diseases - the ones that matter to most people - genetic information indicates only a rough range of probabilities. This sort of prediction falls far short of a diary-like probabilistic future.

I've suggested a different metaphor. Begin with the notion of a diary. Instead of imagining your genome as what is written on the pages, imagine instead that your genome has something to say about how thick that book is. How many pages are we going to have available to write what is important to us? Some of the pages will be nice, smooth paper, easy to inscribe whatever we wish. Other pages might be more rough, more difficult to write upon. If our genome is a diary, it's so primarily to the extent that it helps to determine the physical form of the volume. What stories we write in that diary are ours to write; they are not determined by our genes.

Some of the same concern for genetic information led to work at the National Bioethics Advisory Commission. The issue of what to do with human biological materials in research has become a controversial issue among scientists, physicians, bioethicists, and policy-makers. I've lost count of how many position papers we ultimately found; it might be a dozen, each of which declared what must be done with human biological materials, also known as human tissue samples. These various position papers came to many different conclusions. NBAC was asked to analyze the issue and make its own recommendations. Some of you may know who Tom Lehrer is—the author of many witty songs. One of them was about a Russian mathematician Lobachevsky. There's a wonderful line in that song where Lobachevsky offers the advice "Plagiarize, only always call it research." But, we learned at the National Bioethics Advisory Commission that we could actually talk to people, talk to the public, and

listen to them—we just couldn't call it research, because if we called it research, it would have gone through the federal IRB's and the Office of Management and Budget, and we didn't have enough time. So, we held mini-hearings, not research, around the United States where we brought in groups and different communities. We targeted different parts of American society. We asked them a series of questions about what human biological materials might be used for: Were they aware that if they had been in for a surgical procedure that they probably had signed a statement that said, "Anything left over that has been removed from me can be kept for research or education?" We asked, "Did you know that you've probably signed such a statement?" Decades ago, they didn't even bother to ask you; they just kept it. In the past, it depends on the institution, but certainly in some places for a couple of decades they at least asked you. Now, it may be on the same piece of paper that you sign to give consent for the actual surgery, then there's another line that says, "I give my consent for the tissue." We asked people how many of them remembered signing this, and I think in the seven hearings [there may have been a hundred or so Americans who participated], not one could remember signing such a statement. But I'm sure many of them have. We wanted to find out what people cared about. It was not exactly a sustained dialogue, but we spent a day with these various groups of Americans asking them: "What matters about your tissue? Is it O.K. to use it for research? If so, what are you worried about if it is in fact used for research—what are your fears?" Can you guess what their fears were? Insurance discrimination, and the loss of privacy, the two things we've been speaking about. People in every group spontaneously offered those as their primary concerns. It was very important for the Commission to hear these things. We also were interested to find out that folks were enthusiastic, with almost no exceptions, for the use of their tissues in research. Even people who came from groups who might have reason to fear misuse of genetic information were, with rare exceptions, enthusiastic supporters of the use of tissue in scientific research. So, that was an effort to get at public values about tissue samples and other biological materials.

In the last few minutes I want to talk briefly about assisted reproductive technologies and the search for shared values, because the second part of my thesis was something short-circuiting the discussion there. Now, I confess that I did reflect on the crucial philosophical question I've been hearing constant talk about: "Is Viagra an assisted reproductive technology or not?" I didn't reach an answer. I don't want to get graphic about it, but you know, it's not! We do know there are some fierce battles being fought about how many pills per month would be covered by insurance companies—boggles the mind. So, let me talk about the other ones, the diagnostic work-ups, the laboratory tests and procedures, the interventions and manipulations that are performed on people who come in with a complaint of infertility. Are there shared values here, and if so, what are they? If we look at the current situation, the way that Americans actually deal with infertility treatment, we come out with a picture something like this: there seems to be a strong predilection in favor of individual liberty concerning procreation. If people want to try it, and can pay for it, let them do it. So the other piece of that is market freedom. For infertility therapy in the U.S., some is covered by insurance, much of it isn't, even in states that mandate coverage of certain procedures. There is a tremendous reliance on the market as to the decision "What technologies are used and by whom?" We've begun to treat infertility services as well as human gametes, sperm and eggs, and human embryos even as, at least in certain respects, market commodities. All you need to do is get on the Internet and you can actually see lists of sperm, eggs, and I think even some embryos. Many clinics have now turned to having catalogues where they describe the sources of the gametes and embryos. And not just obvious things, but things like hobbies, IQ, all sorts of fairly personal information of extremely dubious connection to genetics.

A sign, at least in my world or to me, that something might be troubling us here is that there are certain lies or rather gross euphemisms being used. People who provide sperm are called sperm donors, but in fact they're paid. Not a whole lot I gather—\$25-50 was the going rate last time I inquired. Women who provide eggs, on the other hand, are paid a great deal more. The going rate was about \$1,200-1,500 per cycle. Someone told me in Manhattan it can be over \$5,000 per cycle. I haven't confirmed that. Of course, it's a more arduous procedure, and in fact, women have to go through a fairly extensive series of procedures: they need to take hormones; doctors hyperstimulate them so that they hyperovulate; we want to get lots of eggs in the recovery cycle—this part is invasive. We really mess around with their bodies in producing the eggs, and I'm not sure that we have very good evidence at this point about whether there are any long-term risks to the women who go through this. There clearly are disincentives on the part of the clinics to find out, for the same reason that employers and the tobacco companies have disincentives about the negative impacts on health of their products and their manufacturing to the workers and then the users of their products. And fertility clinics have disincentives to find out that what they do hurts people. Bear that in mind as we think about this.

So, if we have to use a euphemism, why do we call people who get paid \$5,000 a “donor”? Last time I looked, if I give money to a charity they called me a donor, if I give money to a charity and they give me a nice new car, I'm not a donor anymore—I've just bought a car. They're a vendor, and I'm a purchaser. So, why do we call somebody who provides sperm for \$50 a donor? They're vendors. But, there's incredible persistence in this euphemism, and I think it's because, out of habit, they're afraid of the implications otherwise. That's my view.

The other sign I have that not all is right here, that somehow our values may be offended, is epitomized in your reaction to the story I told at the beginning of my talk. The woman who gets cloned, has the embryo implanted in her, aborts it, and then uses the eggs so she can have her “own child,” i.e., own genetic child. “What's wrong with that?,” some of my colleagues would ask, “Why don't we?”. It's not a trivially easy task to say exactly what is wrong with that. It strikes us as somehow deeply offensive, but I think we need to work considerably harder at articulating just what it is about such practices that violates things that we consider morally very important. With cloning, once we're past the scary science-fiction scenarios, the ones that are totally unrealistic, and if we ever get past the concerns right now for the safety of the technology, it would be completely wrong to use it in humans, if only because it would be unethical human experimentation. Very risky to any children so created, and potentially quite risky to the women. I don't know if you are aware of the latest data out of the Scotland lab that created Dolly regarding a series with another set of sheep using not as radical a procedure—not nuclei from an adult sheep but from embryonic or fetal sheep, which we know are more readily clonable? 46% of the lambs, I believe, were born abnormal, and not a single one of the sheep went into spontaneous labor. So, something's awry in the communication between the sheep embryo and the ewe which is bearing it. They finally figured out they had to induce labor in all of these ewes. It would be unethical, but if we ever get beyond that stage, to the point where it seems at least as safe as other things that we don't raise an eyebrow about, we'll need to engage very deep questions about why we have children, about the relative importance of biological connection, because that's one of the crucial arguments why anybody would ever want to use cloning in reproduction, and about the values we seek in having a family, and the limits, if any, on the value of control. Control is something that particularly folks like us tend to value, but can there be such a thing as too much control? I think the answer is clearly “Yes.”

One of my most vivid memories from my early, first burst of interest in cloning after Dolly was announced was being on *Talk of the Nation*. The very first caller said this was, as I remember it, a wonderful thing, and he wanted to do it so he could raise himself the way he should have been raised. Part of me almost wishes he would do that, if he could, but I wouldn't wish it on the kid.

I'll conclude with this: I don't think we've had the sort of sustained, respectful, and attentive public dialogue that might help us to locate our shared values on human reproduction. The conversation tends to be short-circuited by the "third rail of American bioethics" - abortion. It mostly seems as if proponents on both sides of the abortion debate are often more interested in scoring rhetorical points than engaging in dialogue, at least when they are doing this in public. The spillover from this debate is hurting us in many ways, not least, I think, in the realm of infertility treatment. We've prohibited federal funding of much good quality research that could actually improve our understanding of the causes of infertility and its possible treatments. Ironically, I don't know if anybody intended this, we have fed the growth of an infertility industry that seems more infatuated with entrepreneurship and marketing than with good science or good medicine. We need quite desperately to break out of this cultural, moral gridlock over abortion. Not that we're going to settle the abortion debate itself easily. The rancor, rhetoric, and rigidity that permeate our public conversations about abortion spill over to many areas in reproduction. The effect on us is that only a few values, liberty, markets, "commodification," maximization of choice and control, seem to dominate our practices in artificial reproductive technologies. I believe we need a much fuller dialogue about shared values and human reproduction, and I hope that the kind of project in you are engaged can help us towards that end. Thank you.

If you have any questions regarding this document please call 734-936-1226 or email genpolicy@umich.edu.
Copyright © 2000 Genome Technology & Reproduction: Values & Public Policy Project