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GENETICS & BIOETHICS

Ethical Issues in Genetics in the Next 100 Years

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There is more than enough ethical mud in genetics of 1998 to keep physicians, lawyers, scientists and bioethicists on guard. A majority are unaware of the progress made in routine and exotic genetics, and most are caught off guard by each new technology. At the same time, in the United States most scientists receive no more than a few hours' training in ethics, most physicians take no training in genetics, and it was revealed in 1997 that less than 16% of those who received a prominent genetic tests for susceptibility to cancer were counseled about the choice. The first time most families in the West learn about the practical issues in genetic testing is when a friend or relative needs a test urgently during pregnancy. To make matters worse, apart from bioethics conferences there is still virtually no common public or scientific international conversation about gene therapy, reproductive rights, or genetic patenting. You might think it is a bad time to look ahead to the next century. After all, there is more than enough work to do now: bioethics must be folded into the high school curriculum. Genetics education must be required for every physician, ethics training for every young scientist, and reproductive issues training should be given to every minister and politician. These are issues for today. With our attention focused on the technology of the month (in 1997 these included cloned sheep and monkeys, babies from frozen eggs, headless frog embryos, a 63 year-old mother, sperm from dead men, and septuplets) we seldom take the time to accomplish even these contemporary objectives. Bioethics is growing quickly but it is unlikely to catch up with science. In such a world it is difficult to spend time forecasting or critiquing future utopias.

However, if the problems of today and the need to remember historical atrocities in genetics are important, it is just as critical to plan ahead. The next 100 years will see changes more dramatic than the 20th century, which saw the creation of molecular genetics, the rise and fall of eugenics, and the creation of a U.S. and international human genome mapping effort. It is time, I believe, to use some imagination to think about what might come to be in the world of genetics in the next 100 years. Only by looking at the long-term outcomes of our current genetic research will we see the compelling need to confront the most basic questions posed by genetic medicine. And, in any event, it has not escaped the attention of this author that it is no more dangerous to exercise a little imagination about our future than it is dangerous to fail to be prescient about possible surprises, such as human cloning.

One shape in the crystal ball is not difficult to discern. Some areas of genetic medicine, such as the effort to identify simple genetic etiology for complex diseases and traits, will plainly begin to fall away during the next few years. Genetic diagnosis and gene therapy will become more and more effective as partners to environmentally- and nutritionally-based medicine and pharmacology. Costs of genetic services will fall precipitously just as evidence accumulates about the costs associated with having particular genes. Virtually every culture will have to cope with an unparalleled pressure to conserve social resources by applying pressure to individuals in an attempt to modify their reproductive behavior and other life choices.

One very important role of bioethics is to think about how allocation of resources, crafting of laws, and education of children and professionals should be used to prepare for such a future. Bioethics can be "institutional criticism," examining how the establishment and maintenance of different institutions puts each society in a position to cope with issues in health and science. However, history is a very poor guide in this regard. Bioethics as a discipline is scarcely 40 years old, and American bioethics has grown out of reactions to big scandals, such as those chronicled at the trials in Nuremburg, Tuskegee, Henry Beecher's study of abuses in research, Baby Doe, and xenotransplantation. Bioethics knows how to react to Dolly the cloned sheep. It is not so great at predicting or laying the ground for new science or paradigm shifts in medicine. It is clear from the public reactions to Dolly, and other recent scientific claims in the areas of developmental and molecular genetics, that bioethics has not done much to improve the potential for sustained conversation about genetics. The danger is that when scandals about Viagra or Prozac or cloning finally grow tiresome, the public's uneducated fear is replaced by untutored acceptance of new technology. Without reconstruction of the institutions of society to meet new challenges, there is little chance we will be prepared for the innovations that are coming.

In this essay I describe three kinds of change that seem to be approaching in the next 100 years. For each of the three waves of coming change in genetics, I have thus concentrated on the kind of institutional weakness--and thus the kind of opportunity for reform--that is present.

A Vision of Making Babies

First, I think it is easy to imagine a world 100 years from now in which parents have much more control over the inheritance of children. Gene therapy and pre-implantation diagnosis for 6-8 cell embryos will be thoroughly assimilated into obstetrics technologies. Indeed all that remains for such technologies to be assimilated are a few technological advances. First scientists must improve the ability, and reduce the cost, of successful in vitro fertilization. Second, in vitro fertilization (IVF) must be made more intimate, more thoroughly integrated with sexual reproduction. Couples who are not infertile will be reluctant to use pre-implantation diagnosis until it is integrated, or at least not so dissonant, with sexually-initiated and consummated reproduction. Infertility treatments today are in the dark ages in this regard. IVF is difficult, painful, risky, expensive, and culturally stigmatized. But advances are likely. Think of this century. The birth control pill revolutionized sex by making it possible to have sexual relations without having children. The pill thus increased the control couples and individuals have over the meaning of their pregnancies. Similarly, Viagra promises to make sexual reproduction still more "voluntary" while retaining the sense of intimacy associated with the use of sexual organs in reproductive activity. In the next 50 years pre-implantation diagnosis and infertility treatment will advance from a clinical and impersonal process to something more realistically sexual in nature. Whether it is a pill, a method for extracting the products of sexual relations, or a non-invasive mode of in vivo gene therapy, there will be a way to integrate genetic diagnosis with other more ordinary reproductive activities. Today's public fears of genetic diagnosis assume that the use of such technologies will be alien, impersonal, and technologically difficult. But these fears can be allayed. At that point there will be widespread calls for the

use of early embryo diagnosis. Couples who are not infertile will begin using diagnostic processes to sort embryos for desired characteristics.

How much should parents be able to use such technologies to design their offspring? What are the moral objections to design of offspring that are most useful in initiating public conversation? In my research group, we closely watch debates about uses of reproductive genetics. These matters are highly politicized. One the one side there is enormous emphasis on the "rights" of individuals. A large number of my colleagues around the United States hold that we need to deal with prenatal diagnosis in the way that we deal with all matters of pregnancy, that is, in terms of the need to preserve the rights of women to choose about their desired outcome. In the U.S. this trend began with Court decisions in this century about abortion, which emphasized the importance of allowing parents to choose to be parents. The present US and European policies allowing infertile and fertile couples to do as much as they like with genetic testing are rooted in reproductive rights.

Others disagree. The countervailing trend in global law is toward thinking of pregnancy in terms of the health of the fetus. This century has seen increasing technological advances around pregnancy, prenatal care, and neonatal intensive care. Pediatric care of young children has similarly advanced dramatically, so that in the 20th century a physician can define the "normal" child in terms of some more or less fulsome body of epidemiological data about whether a particular child has traits that are typical of the last 100,000 or so children seen by physicians. The idea that parents have a responsibility to make sure that their fetus has the opportunity to flourish is an old one, but new technologies have made that responsibility more tangible. Today a pregnant woman who wants to give birth will be strongly encouraged to seek prenatal care and to eat a particular diet. The law in many nations makes parenthood revocable for cases of neglect or abuse. Tomorrow we will likely see outright pressure or even requirements that parents think of their offspring as having a right to flourish. Bans on cloning take as a given the state's compelling interest even in preventing the conception or in vitro creation of offspring who might be placed at risk by the technology.(1)

How much do we want to allow or encourage parents to think of reproduction as a process of "making" rather than "having" babies? I have argued in my recent work that research shows that children who are the product of high-technology pregnancies and neonatal care are more likely to think of their lives in different ways.(2) The clone will be a different person. But how different? How will it feel to be born as a child of this new era? I believe that there are opportunities to think about this future that steer a path between the simple rights of mothers on the one hand, and the mandates of prenatal care on the other. Debate about new reproductive technology so far has focused on laws that would ban particular technologies like cloning. It is time to draw on other social metaphors. The one area where there is widespread consensus about how unorthodox pregnancy should be handled is the area of adoption.(3) Adoptive parents are required to show that they are capable of helping their children overcome what is otherwise a strange new relationship. Policymakers must seek consensus-oriented and procedural methods of forming policy, rather than chasing the hopeless goal reconciling a priori fetal rights with a priori maternal autonomy. New genetic manipulation can be an important tool for parenting, but its responsible implementation depends on assessing the motives of particular parents in the same way that we assess the motives of couples who would adopt. Not every 63 year-old will be a good mother. Most parents would have trouble raising a clone. The key is education to enhance the public's interest in and ability to apply their conventional standards about children's rights to these new technologies.

A Vision of Lifeguards at the Gene Pool

The second element of our genetic future is public health uses of genetic testing. The future is likely to involve some public pressures on adults and institutions to avoid passing on some alleles. The pressure in the next 20 years may come from insurers, but in the long term there will be comprehensive practice guidelines in medicine, embodied by various medical associations, insurers, global health organizations and governments, that could lead to national and regional policies. These policies will make it difficult to pass on genes that are associated with particularly bad outcomes. There are many fears about such a future. What is a "healthy" public? How are we to draw a line between responsible stewardship of the future on the one side, and dangerous abuses of the power of creation on the other? I want to comment on only one aspect of this issue, namely the relationship between public health genetics and eugenics.

Leaders and societies have committed atrocity in the name of plans to improve the public's genetic inheritance. In Western political and philosophical history, from Plato to Aristotle to Hobbes, our deepest ideas about human nature have been rooted in crude, non-molecular accounts of human heredity, many of which have been used to explain or fortify education, health, and political practice. Some of the most significant ethical mistakes of our lifetimes have been made by those acting in the name of purifying public health or "hygiene." Eugenics was taught as scientific fact in the world's finest universities until 1945, sanctioned in global court decisions, and led to the sterilization in the 1920s and 1930s of more than 20,000 in the U.S., 45,000 in the U.K. and 250,000 in Germany.(4)

Eugenics turned public opinion against public control of reproductive choices or communal control over what kind of children will be born. However, in fighting against eugenics, we have only one, highly ineffective safeguard, so-called "non-directive" genetic counseling. Most genetic professionals take the wise lesson that it is wrong to attempt to persuade families about genetic choices. It is a merit worthy ideal. However, not only has the ideology of non-directive counseling been ineffective in preventing counselor or physician bias (as study by Wertz and Fletcher suggests⁵), it has completely ignored the role of economics and social context in pressuring families. If the genetic counselor is available only for families who can pay for the testing, such counseling is by definition directive, namely directed at helping those who can pay. Likewise, how are genetic counselors to protect us from eugenics in a future where state-sponsored genetic screening seems unavoidable? A genetic counselor cannot be non-directive about a test if the test is mandated. The genetic counseling role is likely to expand in importance, whether genetic counselors are around or not. However, the chief sin to be avoided is not directiveness but rather inappropriate pressure.

None believe that we will return to the sterilization practices of eugenics. But public sponsored genetic testing programs will make it likely that more parents will use genetic tests as a part of planning for birth. The public in many nations will begin to pressure families to avoid births where discrete genes can be identified as disease-related. How is the public to be defined for such a purpose? Who will choose which traits to include in screening efforts?

Before we can answer such questions there must be a comprehensive global public health effort to regulate the spread of genetic testing, and in particular an effort to establish global cooperation in assessing the efficacy of genetic tests and the relationship between particular genes and environments. There must also be a new emphasis on retraining journalists, politicians, and ministers about genetics so that genetic testing will not always result in hysteria about eugenics. The debate about eugenics is not helpful in thinking about genetic testing, and in fact has resulted in the development of institutions that hardly protect us from anything, least of all eugenics. Careful, cautious progress into the future of genetic public health policy depends on the establishment of new institutions whose task is to link environmental, genetic, and policy information. Genetic counseling is great, but there are only 1,300

genetic counselors in the United States and a scant few elsewhere. It is thus more important that we ensure that the conceptual resources of genetic counseling are present in clinical services of all kinds. Families must be able to turn to someone, even if only a minister, to interpret and cope with the new issues. These professionals will be directive, reflecting the culture and meaning of their professions and societies. However they must bring concern for the family and individual liberty to the table as well.

A Vision of Genetic Myopia

The third issue for the future is perhaps the most difficult one. It is clear that the maldistribution of public resources in health care cannot continue in the U.S. or other countries. The U.S. spends billions on genetic research and biotechnology, yet still is unable to spend pennies on public health prenatal services for all pregnant women. Americans spend millions on genetic research concerning intelligence, but find their institutions unable to spend pennies to educate the world's children to the point where comprehensive understanding of, and informed consent for, genetic services is possible. This is dangerous because it suggests that we hope for a future in which nutrition, education and environmental issues are sublimated to genetics or genomics or gene therapy.

Perhaps the key and overriding institutional issue in the future of human genetic science and medicine has to do with what we might call "genetic exceptionalism." To allow the mapping of the human genome to occur quickly and auspiciously, several governments created special programs for mapping and sequencing. To allow gene therapy to be separately examined, at least two countries created special regulatory bodies. In the U.S., more than 10 states have laws prohibiting genetic discrimination, but not non-genetic discrimination. These programs and others create the idea that genetics is exceptional, different, and meriting its own category of analysis and regulation.(5)

At times genetic issues are exceptional. Genetic predictive information is different than cholesterol testing. Giving a child gene therapy in the germ line is different from giving her insulin. But in general, the result of thinking about genetics by itself, rather than in the context of other similar technologies, has been excessive spending on gene research while public health goes unfunded. And in no small part, genetic exceptionalism has also licensed hyperbole about "holy grails" and "unlocking the key to life," language that is not only misleading but also damaging to public understanding. My final suggestion is thus that in a future where public health genetics, parenting by genetic test, and new reproductive technologies are part of our life, we must reconstitute our social institutions so that it is possible to fund, discuss, and regulate genetics in the same way we think about its competitors: environmental medicine, nutrition, and public health. We must learn our lessons not from a new "gen-ethics," but from the wisdom of generations applied by analogy.

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