Genetic Ethics Annotated Bibliography

Issues:
Genetics

The following sources do not necessarily reflect the Center's positions or values. These sources, however, are excellent resources for familiarizing oneself with the all sides of the issue.


In *Future Perfect*, Lori B. Andrews cautions that advances in genetic technology may in fact represent dangerous setbacks for society. Genetic technologies might one day produce "perfect" people, but at what cost? The trend is to blame all manner of disease and even behavior on genes, and the emphasis on genetic testing in all of its forms is based on an almost unwavering faith in the predictive power of one's genetic code. We face our genetic future, the author asserts, in an environment in which gene therapies are already sought even when more conventional therapies are more appropriate, and in which scientists claim that genetic manipulation will provide cures without knowing that this is true. This is especially dangerous because the U.S. lacks a mechanism for analyzing controversial new technologies.

Currently, there are three frameworks for governing the adoption of medical technologies in the U.S.: The Medical Model, in which physicians are the gatekeepers of services; The Public Health Model, which focuses on disease prevention through education, financing, and some mandated interventions; and the Fundamental Rights model, in which public information and choice are key. The author asserts that genetic services are currently offered under the Medical Model, and they shouldn't be. To make her case, she focuses on pregnancy. Screening a fetus for abnormalities creates fear when there is little risk. Some women will feel pressured to abort a baby with an abnormality, while others will bring abnormal babies to term and feel guilt because of it. There are implications for the child: the parents might treat a child with an abnormality differently and create a self-fulfilling prophecy through which a child expected to exhibit compromised function actually does so. On a larger societal level, if most people choose to abort those with
abnormalities, society may become less willing to provide services to those with disabilities. Moreover, eugenics in the past has disadvantaged more than just the disabled (e.g., women and people of color, among others), and there is no promise that this will not occur in the future. The problem with placing genetic technology under the Medical Model is that there, "the mere existence of a technology contains an implicit coercion to use it." The author argues that the spread of individuals' genetic information, combined with the belief that such genetic information is virtually foolproof, creates the danger of discrimination on the basis of one's genetic predisposition. To avoid this, she argues that genetic technology should move from the Medical Model to the Fundamental Rights Model. This will ensure that people have control over the genetic information generated about them, as well as over access to it, and will prevent discrimination based on genetic information.


Ruth Hubbard and Elijah Wald describe what they see as the morally, intellectually, financially, and politically shaky foundation of genetic research in Exploding the Gene Myth. The authors assert that genetic science--and indeed all of science--has succumbed to reductionism of the worst kind. Rather than dealing with the entire human being, genetic research has reduced persons to the sum of their genes. On the face of it, the authors assert, this is absurd. The Human Genome Project aspires to reach an "understanding of human beings" and even uses patently religious terms to describe their quest: seeking "The Holy Grail," reading the "Book of Life," and so on. The assumption that a certain DNA sequence defines a human being is questionable at best when science itself is able to answer questions about humanity--indeed the world and life at large--only within specific, narrow contexts. Such an assumption leads to many unfortunate outcomes, which the authors outline in detail. Chief among these is the focus on genetics itself, which in recent years has led to the funneling of time, energy, and money away from the development of other worthy research, cures, and treatments. Indeed, the authors assert that many "genetic breakthroughs don't make people healthier; they merely blame genes for conditions." So you don't have the cancer gene: does that mean smoking isn't bad for you?

Having discussed the limits of science, the authors go on to probe the limits of scientists themselves. Detached observers or not (the authors assert that they are not), scientists are constantly making decisions about what is important, what research to pursue, and so on. Such decisions have grave implications, as in eugenics. In the "Old Eugenics," so-called aberrant traits were defined and steps were taken to wipe out those traits. Given the cultural definitions of any given time, this translates into the use of heredity to reinforce social status. Has the recent focus on genetic research introduced a "New Eugenics?" The authors believe that this is indeed the case, as it is not uncommon to hear people recommend forced sterilization for welfare mothers and prenatal screening has become routine. While they believe it is a woman's right to have an abortion, the authors also assert that being handicapped is not something that automatically deserves a death sentence: there is a qualitative difference between not wanting a child, and not wanting this child.

The authors also provide an overview of genetics and genetic diseases. Here they emphasize the leap that scientists make when they go from pointing out genetic causes of physical
conditions to suggesting that genetics can explain human behaviors. This concept has been accepted by the public simply because people tend to endorse "facts" that confirm their preconceptions. The authors go on to explore what they see as the financial, medical, political, and cultural problems with the current climate of genetic fascination. Among these concerns are: money and research drawn away from other viable areas of research; the questionable influence of big business and big money on the direction of genetic research; the likelihood of genetic discrimination in the realms of education, employment, and insurance as emerging technology makes the once unthinkable possible; and the issues surrounding privacy and civil liberties as it becomes possible for government and corporate entities to collect and utilize our genetic information. In the end, the authors assert that being ill or disabled is part of being human. To conquer illness and disability, through any means and at any cost, is not necessarily the penultimate goal for humanity.


In *The Ethics of Human Gene Therapy*, LeRoy Walters and Julie Gage Palmer strive first to explain clearly the mechanics of genes and gene therapy and then to present a balanced view of the ethical questions raised by advances in genetic technology. The authors ground the discussion in a thorough (albeit concise) exploration of genetic science, the role of genes in disease, and the history of gene therapy. They then analyze the types of gene therapy currently being practiced and explored, discuss possible future applications of gene repair and replacement technology, present the key ethical questions raised by those therapies and applications, and provide the reader with their own conclusions.

In their discussion of somatic cell gene therapy, the authors place a great deal of weight upon public opinion polls and, perhaps more tellingly, upon the "consensus view of the experts." While they concede that such a consensus does not certainly ensure that the therapies in question are ethically acceptable, they believe that people will be less likely to make a "serious moral mistake" if they are guided in some part by this scientific moral majority. In subsequent discussions, the authors again appeal to public and expert opinion to inform their conclusions. In their discussion of the somewhat thornier issues surrounding germ-line gene therapy, the authors provide a thorough exposition of arguments for and against such genetic manipulation, but seem to base their own conclusions in large part on assumptions that they themselves bring to the table. For example, it is not particularly troublesome to excuse what the authors acknowledge as the termination of the life of an embryo or fetus in pursuit of research if one assumes that the greater good of society at large is the overriding moral concern. However, the authors fail to consider the fact that many moral frameworks do not share this assumption. Elsewhere, the authors again place their faith in the majority as they posit that political pressures brought to bear in democratic societies will prevent the misuse of genetic technology by tyrants and dictators. This assumes, of course, that the greater nature of humanity is generally good and that people are collectively willing and able to act in a consistently right way. In the end, the authors take what can fairly be described as a moderate position: they advocate voluntary programs of genetic intervention and are "hopeful" that such interventions will, in time, be limited to sperm and egg cells.
The authors go on to evaluate issues surrounding the potential for physical, intellectual, and even moral enhancement through genetic manipulation. They see a qualitative difference between the desire of a mildly retarded child's parents to genetically enhance their child's intellect and the desire of a normally functioning child's parents to unnecessarily enhance their son's or daughter's intellect. While they regard the former as a noble act, they deem the latter as unacceptable. The authors fail to address the problems that might arise if, for example, the once mildly retarded child becomes many times the intellectual superior of the "normal" child for whom such enhancement is unacceptable. The authors also do not provide definitions by which parents would or would not be allowed to make such genetic enhancements--i.e., who defines when such enhancement is "necessary?"

The authors conclude the book with a brief overview of public policy concerning genetic engineering and several technical appendices concerning genetics. They also include a set of "Points to Consider" regarding genetic manipulation that were developed by the National Institutes of Health Recombinant DNA Advisory Committee.


_The Black Stork_ explores eugenics in American medicine and motion pictures. That it might surprise readers that a book could be written on such a topic is not lost on author Martin S. Pernick: it was no simple feat to track down and view the last surviving viewable print of the book's namesake film. _The Black Stork_ was a movie that championed the cause of Dr. Harry J. Haiselden, who in 1915 began to argue against treating babies who were born with deformities. He asserted that humanity would be better served if such babies never survived to propagate. In the film, which starred the good doctor himself, a man with an inherited disease is warned against marrying. The man marries anyway, and a child is born. The baby requires immediate surgery in order to live, but the doctor refuses to operate. The mother is torn, but is persuaded to let the baby die when she has a dream in which God shows her the child's future--full of pain, misery, and crime. Enlightened, she agrees to forego the lifesaving surgery, the baby dies, and the audience is treated to a vision of the baby's soul leaping into the arms of a waiting Jesus.

Reading about Dr. Haiselden, one is reminded of another, more recent "right to die" doctor: That few if any remember Dr. Haiselden and his equally notorious, headline-stealing activities is in large part the focus of the book. The doctor, while "scrutinized," was never charged with a crime and quickly became the darling of eugenics proponents. Haiselden's supporters believed that science could provide an objective way to resolve social and ethical questions. Those in the know understand that this means that such questions are a matter of simple math: if the greater good is served by the infanticide of a few unfortunate children, so be it.

Certainly, infanticide is nothing new, and Pernick outlines its history in detail. As unthinkable as the concept may have once been, a survey of opinions in the prime of eugenics shows that, in concept at least, it was as popular as ever in the early part of the twentieth century. _The Black Stork_ linked class, ethnicity, and race to hereditary defects, making clear why eugenics appealed to groups in society who held particular judgments regarding race. It also reflected clearly the eugenic ideal of perfection, required a faith in science, and presented an alternative that meant
nothing less than the loss of civilized society to subhuman chaos. Eugenics stepped boldly forward into the ethical quagmire, holding forth objective science as its saving grace.

While prominent eugenics leaders prior to Haiselden had stopped short of publicly advocating death for the unfit, Haiselden blurred the distinction between taking active steps to end life and withholding treatment to let a baby die. In fact, Haiselden was careful to make the distinction himself, garnering support as he did so. However, Haiselden’s practices went the way of eugenics itself, as he began taking ever more active measures that eclipsed his earlier professed views. (For example, he let babies bleed to death by leaving their umbilical cords untied, or gave them lethal doses of opiates.) Why let nature take its time, when you could reach the same end with speedier methods? In short order, Haiselden’s supporters fell away, and in time most "forgot" that they ever agreed with him in any way.

Pernick is quick to point out that the science behind eugenics proved to be less than objective when few could agree on when it was right to let a baby die instead of killing it, or where the line between "fit" and "unfit" should be drawn. Indeed, the arguments had more of a religious tone than scientific, as proponents saw it as a moral duty to eliminate, or allow to die, those whom science had pronounced unfit to live. The debate over eugenics and euthanasia has continued, and it is striking how the memory of Dr. Haiselden has diminished in the meantime. While our understanding of heredity has advanced a great deal since the prime of eugenics and most in society are well aware that history has shown the dangers of mixing science and ideology, Pernick sees disturbing continuities. We hold exaggerated expectations of the utility of genetic information and a faith in the power of genetic science that overreaches the limits of its capabilities. In fact, the same values that propelled principles of eugenics into genocide--or "ethnic cleansing" if you prefer--are still alive today.


In Playing God: Genetic Determinism and Human Freedom, Ted Peters brings his knowledge--theological and scientific--to the discussion of the ethical questions raised by genetic manipulation. The central theme of Playing God is the concept Peters calls the "gene myth": in short, that who and what we are, will be, and ever possibly could be is defined by our genes. Peters asserts that this genetic determinism is not only unsupported by science, but it too easily dismisses the concept of personhood: it focuses too intently on our biological "hardware," so to speak. Regardless of our genetic makeup, we as persons are still free, and as free creatures we are also morally responsible. Consequently, Peters concludes, we are responsible to build a better future through genetic science.

Peters views our ability to manipulate genes as an outgrowth of our human creativity, and our human creativity as an outgrowth of divine creativity. Because we are in fact "co-creative" beings, Peters argues that no less than a proper understanding of God is necessary to ensure that we approach the dawning era of genetic science with the proper ethic. "Playing God," as defined by Peters, is engendered in three activities: learning God’s awesome secrets; wielding power over life and death; and using science to alter life and influence human evolution.
The gene myth dictates a determinism that, at its core, removes from us all responsibility for our actions. We need not then concern ourselves with the implications of what it means to manipulate those very genes in any way we see fit. The gene myth bids us to move ever blindly forward, while the concept of redemption offered by God urges morally free creatures to temper their creativity with wisdom. Having the knowledge to do something, after all, does not automatically imply the wisdom needed to use that knowledge properly. In the end, however, our moral freedom is too big and basic a thing to ignore, and the gene myth must be answered by a concept of human creativity in which "the self orients itself to a good that transcends the self."


In *Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are*, Barbara Katz Rothman looks at genetic science from a sociological perspective. Taking this approach affords her the ability to look at the broader implications of our evolving views of genetics for the world at large. Rothman asserts that, in her view, developments in genetic research have been costly and may in the future very well prove disastrous in ways we can only begin to imagine. Already, she asserts, genetics has migrated from science to ideology, to the point that every major issue of our time has been placed within the context of genetics: whatever the question may be, genetics is likely the answer. This is particularly dangerous because, contrary to what many believe, genetics cannot predict traits. Rather, genetics is akin to meteorology: it provides some measure of predictability and no measure of control. It takes the introduction of very few variables to render much of that predictability useless. Certainly, some of the predictions that genetics affords are absolute (as in the case of some genes that are indisputably lethal), but many other predictions are merely probabilities.

The broader question surrounding genetics and its influence on society has to do with how we handle those probabilities. In a larger sense, the question must be asked: does genetics in any respect provide a level of certainty that warrants the direction in which research is taking society? The author explores this question by dividing the book into three main sections: "Mapping the Past: The Macroeugenics of Race;" "Writing the Body: The Genetics of Illness;" and "Imagining the Future: The Microeugenics of Procreation."

In the first of these sections, Rothman examines the attempt to look at our evolutionary history in the Human Genome Diversity Project. By collecting DNA samples from 25 individuals in each of several hundred groups of indigenous peoples around the world, the project strives to tell us how we became who we are. Such an attempt provides a perfect example of how assumptions about genetics can lead to misperceptions in how we see the rest of the world: such a project is by its nature based on a presumption of difference and is therefore certain to show a difference. The project does not on any level take into account the fact that human beings are also social beings who develop into who they are, both as individuals and societies. Further, the project treats "human population diversity as if it were species diversity." We are all one species, and implying otherwise is racist. The author sees such attempts to view humanity purely in genetic terms as the first steps toward a world where race is a system of power and oppression, and genetic thinking is used to support that oppression. Indeed, this has already happened several times in
the past, and the author points to the publication of *The Bell Curve*, in which the authors assert that African-Americans have a lower IQ, as a recent example.

In "Writing the Body: The Genetics of Illness," Rothman sees racist implications in the way genetic screening is used. When African-American babies are found to have sickle-cell anemia and their mothers feel pressure to abort them, what are the long-term societal implications? In a time when we are already focusing on genetics to the exclusion of other potential causes and cures, those implications seem dire.

Rothman examines such implications more fully in "Imagining the Future: The Microeugenics of Procreation." The combination of abortion and genetic testing increasingly makes mothers the "gatekeepers of life." With greater frequency, abortion is seen as a responsibility that a mother may owe her unborn child. And yet, such a climate ignores the most fundamental question: how terrible must the condition of a child be that no life at all would be preferable to the life he or she would have if allowed to live? Who makes this determination? While women who have had abortions based on the results of genetic testing view themselves as grieving mothers, doctors and geneticists don't see this: they believe they have in some way helped these women.

Regardless of where genetics may be taking us, it is clear that those practitioners on the forefront already regard the available technologies as a way to in some way control the uncontrollable: life.


On June 9 - 10, 1994, the U.S. Department of Energy sponsored a workshop on Medical Information and the Right to Privacy. The book *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* is a product of that workshop. The book is comprised of articles by 22 authors and is divided into five sections, covering the background of genetics, genetics in healthcare, the effects of new technology, non-medical uses of genetic information, and ethics and law in the United States and abroad. The articles focus on the legal, scientific, and ethical issues surrounding genetic information and privacy. Editor Mark A. Rothstein ends the book with his own recommendations on such issues.

"Genetic Secrets: A Policy Framework" draws on the previous authors to present a strategy for regulating genetic information. Many of the problems created by genetic information can be eased through education and voluntary approaches, but ultimately new legislation is required to protect genetic privacy and confidentiality. Genetic conditions should be part of broader medical privacy legislation because it is difficult to separate genetic and medical concepts: there are genetic components to many health issues. Further, health care providers must be trained to understand the importance of confidentiality to their patients. Computers must be encrypted to safeguard patients' information, including medical and billing records. The insurance industry needs to be modified in several key ways. Legislation prohibiting the re-disclosure or sale to third parties of information submitted for medical underwriting, as well as discrimination based on knowledge of genetic information, is needed. Laws against discrimination in the workplace on the basis of disability need to be carefully crafted: employers should not be permitted to avoid hiring someone based on his or her genetic probability of developing an illness or disability. State laws regarding school records can be amended to include genetic privacy, and other current privacy
laws could be changed to cover genetic information in commercial uses. For example, it would be easy to imagine a mortgage company wanting genetic reassurance that a homeowner will live for all 30 years of his or her mortgage. In general, genetic privacy will require a view of privacy in general that strives to avoid "discrimination, denial of opportunities, financial burdens, and social disadvantage."


In *Redesigning Humans: Our Inevitable Genetic Future*, Gregory Stock describes the future of genetic manipulation with all of the excitement and none of the dread that one would describe the approach of a runaway freight train. While other commentators have focused on artificial intelligence and the development of machine consciousness as the wave of our future, Stock sees genetic manipulation as the catalyst that will propel human evolution to heights that we can hardly imagine-- though imagine them he does. He predicts that genetic technologies such as germ-line engineering and embryo selection will marry robotic and computer technology and reach a glorious crescendo of artificial limbs, cochlear implants, retinal electrodes, DNA chips, and artificial chromosomes. Humans will become, he envisions, functional cyborgs--or "fyborgs." In this way, Stock believes we will remain biological without giving up the benefits that technology affords us.

Germ-line technology will challenge us when it succeeds, which it inevitably will. It will force us to come to grips with the medical, social, political, and philosophical implications of self-directed human evolution. At the same time, the author argues that because we can't fathom the changes this will bring, we shouldn't be too quick to judge them. Whether we'll have time to judge them later, or whether judging those changes has anything to do with coming to grips with the implications of self-directed human evolution remains to be seen. Regardless, germ-line gene therapy is already here, and rather than trying to stop it--for whatever reason we would seek to--we should instead strive to control it by focusing on who will have access to this technology and how it will be used.

The author envisions a future in which there are two kinds of people: the "enhanced" and the "unenhanced." How they will relate to each other is a mystery: perhaps they will take two very different evolutionary paths. Whatever the case, Stock believes that the choice we make will be irrevocable, and he envisions a world where germ-line engineering will render conception in the lab "obligatory rather than optional." Still, the author believes that the benefits of such a world outweigh the risks and puts his faith in a free market and choice as the best means to protect us from abuses.


In *Genetic Testing and Screening*, Evangelical Lutheran Church in America (ELCA) members with backgrounds in science, business, medicine, ethics, and theology were invited to address
the implications of genetic testing from their vantage points. The result is a series of nine essays by authors that include a pediatrician, a clinical geneticist, theologians, a pastor, and the vice president and chief financial officer of a biotechnology company. The book is divided into three main sections: "Understanding Genetic Testing and Screening;" "Engaging Worldviews and Proposing Alternatives;" and "Confronting Professional Challenges."

The first section provides a basic guide to the facts and issues surrounding genetic testing and screening. In particular, it provides an introduction to genetic science, including what genes are, how they function, and what can go wrong in the transfer of genetic information. While this is certainly straight science, its implications are far-reaching, and as our knowledge increases, it will be up to religion to provide the wisdom needed to properly wield that knowledge. In her essay on genetic counseling, Kirstin Finn Schwandt uses vignettes of composite and real cases to illustrate her points. Genetic principles are so complex and the consequences of genetic science so important that the role of genetic counseling and education cannot be separated from the use of genetic technology. Unfortunately, genetic counselors are not trained to focus on their patients’ faith, and the church is not genetically literate enough to understand and converse with people struggling to make genetic choices. The first section concludes with an analysis of the way in which breakthroughs are translated into available procedures and a consideration of the values of the biotech industry. There is no "sinister master plan" behind genetics, and in fact many on the forefront of genetic science are people of faith. Not only must the church understand that the knowledge God has given us about our genetic makeup is a gift, but it must be present and active in the conversation about genetics in order to affirm that we are more than just the sum of our genes and that God transcends our genetic makeup.

In the second section, "Engaging Worldviews and Proposing Alternatives," the authors discuss the societal and moral dangers and challenges posed by genetic testing. Genetic testing and medicine are governed by a prevailing worldview, one that sees people principally in terms of production and consumption. The church faces a challenge in not simply confronting this worldview, but interacting with it. To do this successfully, the church must provide a community that respects Christian freedom and that acknowledges differing perspectives. By respectfully engaging the prevailing worldview, there is hope for a more "wholesome worldview" to emerge. This is made more challenging when one considers the different ways that the church and the world at large view issues such as social dignity, personal identity, responsibility, and conscience in light of the implications of genetic science. Indeed, as Ted Peters points out, the dangers inherent in mixing genetic powers with social and economic pressures are many and dire, including widespread selective abortions and the treatment of children as commodities. The church must respond to the complexities of genetic and sociological ethical questions with a simple truth: "God loves each human being regardless of genetic makeup, and we should do likewise." Hans O. Tiefel goes on to point out that while genetics gives us knowledge of disease and disorder, it gives us no explanation. The church must see the knowledge revealed by genetic testing as a shared responsibility to be confronted in the presence of God.

In the third section of the book, "Confronting Professional Challenges," Robert Roger Lebel looks at the age-old question of whether faith can live with science. For his part, Lebel sees God at work in the evolution of the universe, including humanity. Ultimately, all of creation will be unified in Christ, and humans have been carried along this path in such a way that we have now arrived "at the cutting edge of evolution and [are] presented with the power and challenge to direct its
course." While evil is at work in every way in the physical world and in every science that applies to that physical world (including genetics), the Holy Spirit is also at work. We must not shun the science of genetics or be afraid of what it means to be able to read our genes and understand what they say about us. In the closing essay, Lawrence E. Holst refers to genetic testing as "lifting the veil of innocence." As such, the pastor should serve as a companion who walks with people through the genetic tragedies of life, just as he or she would walk with people through any other tragedy.

Updated February 2003

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