

Genetic Testing & Discrimination

Lecture 8

Genetics & Society
Honor 3215, Spring 2009
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Genetic Information

- The more we learn about genetics (inevitable), and the easier (computing power) and cheaper (~\$1,000) it is to sequence individual genetic information the more that information will be part of our personal and social decisions.
- Health providers will provide tests, but there are also companies willing to sequence your genome for a fee...

Questions:

How should we understand this information?

Who is interested in this information?

Who should have access to this information?

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Genetic Tests

- **Health related**
 - Illness, family history, reproduction, etc.
- **Identity**
 - Forensic, lost remains, etc.
- **Ancestry**
 - Adoptees, family, human history, etc.
- **Also**
 - Dating, matching children to right sport, curiosity, etc.

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Genetic Health Tests

- | <u>Promises</u> | <u>Perils</u> |
|-------------------------|--|
| • Early intervention | • Interpreting Risk <ul style="list-style-type: none">– Risk Factors?– Predisposition vs. Disease |
| • Future decisions | |
| • Personalized medicine | • Discrimination <ul style="list-style-type: none">– Insurance– Employment– Social |
| • Reduce health costs | |

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Personal DNA Testing

Video from *Nova Science Now*

Originally aired July 2008

Available at

www.pbs.org/wgbh/nova/sciencenow

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Video Questions

- How are SNPs used to determine health risk?
- How accurate/predictive are the risk estimates?

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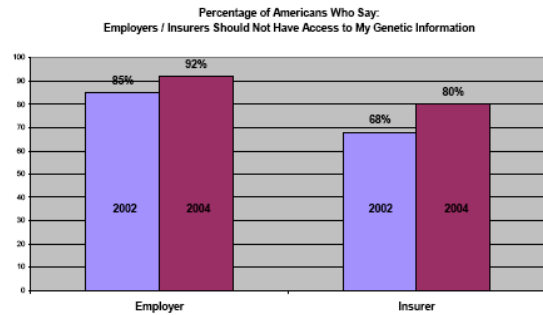
Individual and Social Benefits

“Once informed about their genetic status, individuals can take proactive steps to protect their health, enhance their well-being, and lower health care costs for themselves and society as a whole.”

(*Faces of Genetic Discrimination*, July 2004, p. 1)

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Americans' Growing Concerns about Access to Genetic Information



Source: JHU Genetics & Public Policy Center Survey "Public Awareness and Attitude about Genetic Technologies" (2002, 2004)

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Why Worry?

Genetic Discrimination

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Genetic Discrimination

A working definition

- Discrimination based on one's genetic make-up (genotype).
 - Analogous to sexual or racial discrimination.
 - Should be prevented

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Case 1: Danny

Seven-year-old Danny is in perfect health, but a genetic test reveals that he has a gene predisposing him to a heart disorder. Even though he takes medication that lowers his risk of a heart attack, he is denied health insurance for this condition. His insurance company argues that since his gene has been present since birth, this qualifies as a "pre-existing" medical condition.

Is this genetic discrimination?

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Case 2: Kim

Kim is a social worker with a large human services agency. During a staff workshop on caring for people with chronic illnesses, Kim mentions that she was the primary caretaker for her mother who died of Huntington's disease. Kim herself has a 50% chance of developing this fatal genetic condition. One week after she reveals her risk status, Kim is fired from her job even though she has received outstanding performance reviews in the months prior to the firing.

Is this genetic discrimination?

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Case 3: Mary

Mary has a family history of breast cancer: both her mother and her aunt have been diagnosed with it. She worries about her future and is considering getting tested for BRCA-1, a gene associated with some forms of hereditary breast cancer. Ultimately, she decides not to take advantage of the test, because she fears a positive result will jeopardize her chances for promotion at her job.

Is this genetic discrimination?

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Case 4: Gary

Gary was diagnosed with Carpal Tunnel Syndrome (CTS) in 2000 and took leave from work to have surgery and recover. When he returned to work, Gary was told that he would have to undergo a mandatory medical examination. If he refused to submit to the examination he would be fired. He later learned that his employer was administering secret genetic tests to workers without their consent to identify a possible genetic predisposition to CTS as a defense to workers' compensation claims. Gary refused to take the exam and his employer began disciplinary proceedings to fire him. (Suit by EEOC in 2001, settled in 2002.)

Is this genetic discrimination?

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Legal Actions

- 1995: EEOC issues interpretation of ADA (1990) that outlaws discrimination on the basis of a person's genes, if considered a disability.
- 1996: HIPAA prohibits genetic discrimination by insurance companies and restricts medical information access; for group health plans.
- 2000: (Feb. 8) President Clinton's executive order prohibiting genetic discrimination in hiring and promotion decisions for all federal employees.
- 2008: President signed bill (GINA) that prohibits employers from using genetic tests for employment purposes and health insurance coverage.

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Why is genetic discrimination unethical?

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Three Arguments

1. Unfair exclusion practices
2. Individual and social consequences
3. Moral expressivism*

Autonomy and Justice issues...

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(1) Unfair exclusion

- Amounts to **medical speculation**: Employers and insurers are using the results of genetic tests to discriminate based on perceptions of long-term health risks and possible future disabilities; decisions based on genotype not phenotype...
- Being predisposed to a disease, like skin color, is mediated by genes which lies entirely **outside the individual's control**. Whereas individuals can exercise choices about whether to smoke, how much exercise they get, and how much fat is in their diets, they cannot change the contents of their genes...
- Tests are **used out of context** in ways that are contrary to the interests of a patient undergoing genetic tests for health related concerns; intended for medical benefit...
- To make employment or insurance decisions on the basis of genetic characteristics determined at the moment of conception is to discard cherished beliefs in **justice, equality and autonomy**...

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Genetic discrimination is unfair to workers and their families. It is unjustified – among other reasons, because it involves little more than medical speculation. A genetic predisposition toward cancer or heart disease does not mean the condition will develop. To deny employment or insurance to a healthy person based only on a predisposition violates our country's belief in equal treatment and individual merit.

President George W. Bush

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Principle of Privacy

(Autonomy)

- Information about an individual should be kept under the control of the individual; because it facilitates autonomy.
 - Autonomy: Individuals should be allowed to determine the course of their own life; it should be up to the individual what kind of life he or she lives, consistent with other's autonomy.
- Alternatively, information about an individual should not be used to unduly disadvantage that individual.

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(2) Individual and social consequences

- Fear of genetic discrimination **prevents people from individually benefiting from genetic testing** (prevention or management of future disease) because they fear the loss of a job or health insurance.
- Fear of genetic discrimination also means people are less willing to participate in clinical trials or studies that may involve genetic testing, thus **depriving society from benefiting** from the results of this research.

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We are on the verge of a true revolution in medicine. But there is a chance it will not happen as we hope. It will not be a failure of the science. There is increasing evidence people fear their genetic information will be used to deny them health insurance or a job. This fear is keeping them from seeking medical help. If people believe that a new system of individualized medicine will lead to denial of health insurance or other benefits, they will not take advantage of what the new system could offer. The revolution at hand may not be realized because people are afraid to take part in it.

J. Craig Venter, President and
Chief Scientific Officer Celera Genomics

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Principles of Justice

- Justice = Fairness
 - Individuals (or groups) should receive a fair distribution of goods; a fair (equitable) burden of risk (or cost) and benefit.
- Justice = Equality
 - Individuals (or groups) should be treated the same unless there is a justified reason for unequal treatment.

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Are these arguments persuasive?

Do insurers and employers have a justified interest in genetic information about their clients or employees when it is relevant?

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Insurer's Access

- Risk classification and medical underwriting are essential to insurer's business.
 - Fair distribution of risk so insurers can honor claims.
 - Greater risk = higher premiums, lower risk = lower premiums.
- Proper risk classification makes insurance widely available and affordable.
 - Withholding relevant genetic information would undermine risk classification and thus insurers ability to honor claims.

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Employer's Access

- Employers calculate costs and risks according to employee productivity and health risks.
 - Thus, have an interest in knowing some medical conditions of employees.
 - Cost-benefit analysis of future risks requires this info.
- Many employers insure their employees, so they have same interests as insurers.
 - See previous slide...

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Are the original arguments persuasive?

Argument	Counter-Argument
Mere medical speculation? (Genotype, not phenotype.)	Should calculate potential risks on reliable indicators.
Genotype is not in control of individual?	Neither are they in control of their sex, age, family history which are used to calculate risk.
Info intended only for medical benefit?	Info about health status is relevant for insurance and employment purposes.
Violates justice, equality, and autonomy?	Also apply to others, e.g., insurers and employers. Is it fair for insurers or employers to bear all the risk or costs of medical treatment?
Social and individual consequences?	Without this info insurers and employers risk being unprofitable or, worse, not offering health insurance.

One more argument...

Moral Expressivism

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(3) Moral expressivism

- Certain practices have **moral meaning** that makes the practice unethical, independent of the intentions or consequences of the practice.
 - E.g., I may not intend to spit on someone, and spitting may not physically harm, but if I do, it has the meaning of disrespect towards that person.
- So, understood in the context of the history of eugenics, treating people differently on the basis of their genetic make-up (genotype) is a morally troubling practice.

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Deborah Hellman, 2003

"...the meaning of genetic discrimination may be that those with genetic flaws (or more flaws than average) are less worthy or less important – even if those genetic aspects never see expression – that is, genetic discrimination is directed at genotype (not phenotype)... [G]enetic discrimination is different from discrimination on the basis of health...[it] expresse[s] a meaning that denigrates the equal moral worth of those with genetic predisposition to disease."

(What Makes Genetic Discrimination Exceptional, p. 95)

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In the final analysis...

- Does moral expressivism capture something important about genetic discrimination?
- Does the use of commercial tests raise new worries?

Would you take a genetic test?

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Key Points

- Promises and Perils of genetic testing
- Risk assessment
 - Genes as risk factors
- Genetic discrimination
 - Working definition
 - Analogy with racial and sexual discrimination?
 - Arguments and counter-arguments
- Principles
 - Privacy
 - Justice²
- Moral expressivism

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