



Genetic Discrimination

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What is Genetic Discrimination?

- Unfair treatment
- Loss of opportunities
- Any different treatment that adversely affects the person at risk
 - Example: the denial, limitation or increased price of insurance
- Based solely on genetic susceptibility, not manifest disease

- Genetic discrimination is defined as the denial of rights, privileges or opportunities or other adverse treatment based solely on genetic information, including family history of HD.
- In the questions that follow the term “treated unfairly” refers to the experience of genetic discrimination.

– From the RESPOND-HD survey, 2007

How is genetic information used?



How does your employer see you?



Four areas of concern

- Privacy (the right to control *collection* of genetic data): Others can collect information about your genetic status without knowledge or consent
 - Example: Companies may require a genetic test as a condition of getting health insurance
- Confidentiality (the right to control *disclosure* of information): Having genetic information discovered by commercial entities searching health records for genetic information
 - Example: Commercial entities search through medical records for genetic information

Four areas of concern

- Use of genetic information based on *false* beliefs about the significance of genetic traits
 - Example: Being excluded from a job opportunity because the employer thinks a genetic test predicts higher insurance costs – the BNSF case
- Use of genetic information to make a decision about something of importance
 - Example: Someone at-risk for HD is denied custody of children in a divorce because of the risk of developing genetic disease in mid-life

Genetic Information Non-disclosure Act of 2008

- First civil rights legislation of the 21st century
- Protects individuals from genetic discrimination in *health insurance* and *employment* contexts
- At least 15 years lobbying and awareness efforts by many groups

What is Genetic Information?

- Genetic information is defined as information about
 - an individual's genetic tests;
 - the genetic tests of family members of an individual; or
 - the occurrence of a disease or disorder in family members of an individual

GINA: Health insurance provisions

- Prohibits specific types of access to genetic information
 - cannot require a genetic test (except for payment)
 - cannot request, require or purchase access to genetic information (but may acquire incidentally)

GINA: Health insurance provisions

- Prohibits use of genetic information for certain activities:
 - cannot determine eligibility or premium rating
 - pre-existing condition clause cannot be triggered unless symptomatic

Health insurance limitations

- Liability limited to \$500,000 per violation
- Asymptomatic individuals only: it is not unlawful to discriminate against individuals based on manifest disease
- No protection for life, disability or long-term care insurance

GINA: employment provisions

- Apply to employers, employment agencies, labor organizations and training programs
 - Makes it illegal to request, require or purchase genetic information
 - May not refuse to hire or discharge any applicant or employee due to genetic information
 - May not discriminate with regard to terms, conditions of employment, compensation or privileges based on genetic information

GINA: employment provisions

- Employers may possess genetic information without penalty if voluntarily disclosed
- Incidental disclosures of genetic information are not protected
 - Includes Family Medical Leave Act absences, wellness programs
- GINA provides a prohibition against retaliation for bringing a complaint

Employment limitations

- Coercion: Employers may obtain genetic information after a conditional offer of employment and require an authorization for the release of their medical records
 - ADA § 102(d)(3)

What GINA does not protect

- Other types of genetic discrimination outside the realms of employment and health insurance

Obtaining a mortgage

Legal disputes:

adoption,

custody,

contributory negligence

- Stigmatization of individuals who are at risk for genetic disease

Discrimination

- the denial of rights, privileges or opportunities or other adverse treatment based solely on genetic information
- Overt: forthright acknowledgment of reasons - we cannot afford to keep you on payroll
- Covert: stonewalling, pretext, covering up the real reasons for adverse treatment

Stigma

- Variable causes – disease, social status - leading to a social interpretation of the meaning of a condition
- “Negative stereotypes and isolation” (Sankar, 2005)
- “an attribute that conveys a devalued social identity within a particular context” (Crocker, Miller 2001)
- Subtle actions including exclusion, daily hassles
- Includes major events such as denial of job, insurance

- Internal / self coping mechanisms
 - Meditation
 - Spirituality
 - Psychotherapy
- External / social coping
 - Participate in HDSA
 - Educate others
 - Complain / seek legal redress

Coping with discrimination and stigma

What will GINA mean?

Will it make a difference in how people make health care decisions?

What are the trade-offs you make if you decide to/not to get a genetic test?

Will it make a difference to whom you feel safe to reveal genetic information?

Will you “stand out” *more* if the awareness of genetic discrimination is now raised?