Implementing the Genetic Information Nondiscrimination Act

A Public Policy Forum

Tuesday, February 1, 2011
10:00am-12:00pm
Collaborating Partners

• Employment and Disability Institute
  ILR School, Ithaca, NY

• Dept. of Policy Analysis and Management
  College of Human Ecology, Ithaca, New York

• Mathematica Policy Research, Inc.
  Princeton, NJ, Washington, DC, and Cambridge, MA

• American Association of People with Disabilities
  Washington, DC

• Rutgers University, School of Management and Labor Relations, Program for Disability Research
  New Brunswick, NJ
This forum is a project of the Rehabilitation Research and Training Center on Employment Policy for Persons with Disabilities, which is funded by the US Department of Education, National Institute on Disability and Rehabilitation Research. (Grant Number: H133B040013.)

The content of this forum does not necessarily reflect the policies of the US Dept. of Education, and you should not assume endorsement by the Federal Government (EDGAR, 75.620 (b)).
Introduction:
Susanne Bruyère, Director
Cornell University, Employment and Disability Institute

Facilitator:
Robin L. Shaffert, Senior Director of Corporate Social Responsibility
American Association of People with Disabilities

Speakers:
Susannah Baruch, Policy Analyst and Consultant
Genetics and Public Policy Center, Johns Hopkins University
Chai Feldblum, Commissioner,
Equal Employment Opportunity Commission
Victoria A. Lipnic, Commissioner,
Equal Employment Opportunity Commission
Nancy Hammer, Government Affairs Policy Counsel
Society for Human Resource Management
Susannah Baruch
Policy Analyst and Consultant
Genetics and Public Policy Center
Johns Hopkins University
Genetic Discrimination 101

Susannah Baruch J.D.
Genetics & Public Policy Center
Johns Hopkins University
www.DNApolicy.org
February 1, 2011
Uses of Genomic Information

1. Diagnose Disease
2. Predict future risk of disease
3. Inform reproductive decisionmaking
4. Predict drug response
5. Predict therapy response
Original Purpose(s) of the Genetic Information Nondiscrimination Act

1. Fight fear of genetic discrimination
2. Help individuals
3. Help research (and researchers)
4. New civil rights protections in employment (clarify what some said had been there before: ADA)
5. New health insurance protections (expand previous laws: HIPAA and state laws.)
What’s Genetic Information Anyway?

Information about:

• A person’s genetic tests (GT=assesses genes, mutations, or chromosomal changes)

• Family history, such as:

• Disease or disorder in a family member

• Genetic tests of a person’s family members
What’s Genetic Information Anyway?

Information about:

• Participation of a person or family member in genetic testing, counseling, or education.

• Participation of a person or family member in research that includes genetic testing, counseling, or education.
Some Common Genetic Tests

• Tests for BRCA1/BRCA2 (breast cancer) or HNPCC (colon cancer) mutations

• Classifications of genetic properties of an existing tumor to help determine therapy

• Tests for Huntington disease mutations

• Carrier screening for disorders, such as cystic fibrosis, sickle cell anemia, spinal muscular atrophy, and the fragile X syndrome
What’s NOT Genetic Information:

• Sex or age.

• Routine tests such as complete blood counts (CBC, or blood panel), cholesterol tests, and liver-function tests.

• Analysis, including DNA analysis, of infectious agents such as bacteria, viruses, and fungi, such as HIV.

• Information about a disease that is already manifested (signs and symptoms, diagnosis).
What GINA does not do:

• Protect information about *current health status*.

• Protect information about disease simply because it is genetic, when the disease is already diagnosed and manifest.

• Apply to life, disability, or long-term-care insurers.
What GINA does not do

GINA Does NOT Apply To

- Certain health systems with own policies:
  - United States Military,
  - Veterans Administration
  - Indian Health Service, or
  - Federal Employees Health Benefits program (FEHB).

- Employers with fewer than 15 employees
GINA and Health Insurance

• GINA does not prohibit medical underwriting based on current health status, even if a genetic disease.

• GINA does not mandate insurance coverage for any particular medical tests or treatments - even if indicated by genetic testing.

• New Health Insurance Reform Law will provide
  ➢ *health insurance coverage to uninsured,*
  ➢ *will include some individuals not helped by GINA.*
GINA and Health Care

• Health *insurers* can’t request or require a patient take a test.

• However, a treating health care *provider* (your own doctor) may *request* that a person or family member undergo a genetic test.

• Treating health care professionals should also be taking family histories - important!

• GINA should not discourage taking family history or mean providers are encouraging unnecessary genetic tests.
The Limits of GINA

Not an absolute privacy law:
GINA allows workplace *collection* of genetic information under limited circumstances:

- genetic monitoring
- certain cases of inadvertent acquisition of information.
- some wellness programs
- ADA requests/family and medical-leave laws
Key Issue in Employment Regs

- Wellness programs run in employment settings by health insurers, employers, or third parties

- Includes “Health Risk Assessment” asking for family history -- information flowing where it shouldn’t...

- Big penalties/benefits for not participating.

- When is this ok? When does it violate GINA?
  - Real clinical care
  - Truly voluntary
Chai Feldblum
Commissioner
Equal Employment Opportunity Commission (EEOC)
Victoria Lipnic
Commissioner
Equal Employment Opportunity Commission (EEOC)
Nancy Hammer
Policy Counsel
Society for Human Resource Management (SHRM)
For More Information

http://www.eeoc.gov/laws/regulations/index.cfm

- EEOC Final Rule on Title II of the Genetic Information Nondiscrimination Act of 2008
- Background Information for EEOC Final Rule
- Questions and Answers for Small Businesses: EEOC Final Rule
Related Resources

- Employment Policy for People with Disabilities online repository of over 200 related research reports and policy briefs:
  http://digitalcommons.ilr.cornell.edu/edi/
- HR Tips (over 35 brochures in English and Spanish on workplace accommodation):
  www.hrtips.org
- Disability statistics online:
  www.disabilitystatistics.org
- National Technical Assistance Policy and Research Center for Employers on Employment of People with Disability:
  www.earnworks.com
Thank You!

Please complete the online evaluation which follows.