

Principles for Genetic Discrimination Legislation

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**National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004**

**202-272-2004 Voice
202-272-2074 TTY
202-272-2022 Fax**

Protections for Individuals with Actual Health Conditions: The same interpretations that make the ADA difficult to enforce by individuals with genetic markers make it difficult to enforce by individuals with a range of health conditions. When Congress considers protections for individuals who experience discrimination based on genetic information, it should also ensure that if these individuals are eventually diagnosed with medical conditions, they will be protected against discrimination.

Workplace Discrimination: Employers must not be permitted to use predictive genetic information as a basis for taking any employment actions or as a term or condition of employment. Nor should employers be permitted to use this information to limit, segregate or classify employees or job applicants.

Employers' Collection of Information: Employers should be permitted to request predictive genetic information only: (1) to monitor effects of toxic substances in the workplace upon an employees' written consent to such monitoring, with the employer receiving only aggregate results and not results for particular employees, or (2) to provide genetic services to employees upon the employees' written consent. In either case, results should be provided only to the employee.

Employers' Disclosure of Information: Genetic information must be kept strictly confidential and maintained separately from personnel files and other employee information. It should be disclosed only to the employee, officials enforcing this legislation, or as required by other federal laws.

Insurance Discrimination: Insurers must not be permitted to make decisions about enrollment in health, life, disability, or other types of insurance based on genetic information. They must also be prohibited from using genetic information in determining premium or contribution rates, or other terms or conditions of coverage. They must be barred from requesting or requiring genetic tests.

Collection of Information by Insurers: Insurers must not be permitted to request, require, collect or buy genetic information except for the limited purpose of paying for claims for genetic testing or other genetic services. Strict protections must ensure that when such information is requested, it is not used to affect an individual's enrollment, premiums, or terms or benefits of coverage.

Disclosure of Information by Insurers: Insurers must be prohibited from disclosing genetic information to employers, entities that collect or disseminate insurance information, or health plans or health insurance issuers except in the limited circumstance of payment for claims.

Health Care Discrimination: Legislation must bar health care providers from refusing treatment to individuals, or treating them differently, based on genetic information.

Collection of Information by Health Care Providers: Legislation must prohibit health care providers from requiring, requesting, or collecting genetic information about individuals who are seeking treatment. Providers may only collect this information for the purpose of providing genetic testing or other genetic services.

Disclosure of Information by Health Care Providers: Health care providers must not be permitted to disclose genetic information except to the patient, to insurers only for the limited purpose of seeking payment for genetic testing or genetic services rendered, to officials enforcing this legislation, or as required by other federal laws.

Education and Technical Assistance: Funding should be provided for education and technical assistance in order to ensure that individuals affected by the legislation are aware of its requirements.

Effective Enforcement: A private right of action to enforce genetic discrimination legislation must be included. The EEOC should have authority to investigate and resolve complaints relating to employment. The full range of remedies, including attorney's fees, must be available.

Relationship to Other Laws: Legislation must not preempt existing state or federal laws to the extent that they provide greater protections for individuals who experience genetic discrimination.