Genetic Confidentiality And Discrimination, A Cause For Concern

The mapping and sequencing of the Human Genome has created complex ethical, legal, and social issues. While this wealth of new information has potential for great benefit, there is also potential for great harm. History has demonstrated the misuse of genetic information. The misuse of genetic information can be seen in the U.S. eugenics policies of the early 1900s that lead to discrimination, invasion of privacy, and unethical practices, such as involuntary sterilization of those determined to be "feebleminded." To avoid the exploitation and misuse of genetics that occurred at the beginning of the 20th century, the Human Genome Project established the Ethical, Legal and Social Implications (ELSI) project to anticipate and address the implications for individuals and society of the mapping and sequencing of the human genome. The ELSI project, along with numerous national and state-sponsored task forces, has been responsible for developing legislative proposals to protect genetic information and prevent discrimination. However, these efforts are slower than the scientific advances that are occurring at a phenomenal pace. As science continues to move faster than policy, court intervention is predicted to address issues of privacy infringement and discrimination. A careful review of the Oklahoma genetic needs assessment findings, national advisory group statements, current federal legislation, the executive orders from the President of the United States, and local legislation underscores the concerns that both the public and policymakers have in regard to prohibiting genetic discrimination by employers and insurance providers, and other complex issues related to genetics.

During our genetic needs assessment in Oklahoma, genetic providers were questioned regarding issues of discrimination and confidentially. It was generally reported that patients are fearful of genetic testing and often request the results be withheld from insurance providers. There were no reports of insurance or employee discrimination, but all providers agreed that their patients were anxious about these issues.

The Secretary's Advisory Committee on Genetic Testing (SACGT) was established in 1998 to advise the Department of Health and Human Services on the medical, scientific, ethical, legal, and social issues raised by the development and use of genetic tests. In a SACGT report to the Assistant Secretary of Health and Surgeon General, there was the following recommendation:

> Federal legislation is needed to prohibit discrimination in employment and health insurance based on genetic information. Federal legislation is also needed to protect the privacy of genetic information as well as other medical information in medical records. Without these protections, the public will be reluctant to undergo genetic tests that might be beneficial to its health and well-being (Enhancing 14).[14]

The Human Genome Project's Ethical, Legal and Social Implications (ELSI) project monitors legislation at the federal and state level and reports:

> No federal legislation has been passed relating to genetic discrimination in individual insurance coverage or to genetic discrimination in the workplace. Several bills were introduced during the last decade. Some of these bills attempted to amend existing civil rights and labor laws, while others stood alone. The primary public concerns are that (1) insurers will use genetic information to deny, limit, or cancel insurance policies, or (2) employers will use genetic information against existing workers or to screen potential employees. Because DNA samples can be held indefinitely, there is the added threat that samples will be used for purposes other than those for which they were gathered (Genetics Privacy 1).[19]

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[14] *Enhancing the Oversight...*

[19] *Genetics Privacy Legislation...*

Although no specific federal genetic nondiscrimination legislation has been enacted, there are current anti-discrimination laws that may be applied to genetics including the Americans with Disabilities Act of 1990 (ADA), the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and Title VII of the Civil Rights Act of 1964. The Americans with Disabilities Act prohibition of discrimination based on disability is the most likely current source of protection against genetic discrimination in the workplace. HIPPA is the only federal law that directly addresses the issue of genetic discrimination. Currently the Department of Health and Human Services are proposing modifications to the consent requirements due to the possible interference with the efficient delivery of health care. Lastly, Title VII of the Civil Rights Act might provide protection against genetic discrimination arguing racially or ethnically linked genetic disorders constitutes unlawful race or ethnicity discrimination (*Genetics Privacy* 4).[20]

On February 8, 2000, President Clinton signed an executive order prohibiting every federal department and agency from using genetic information in any hiring or promotion action. A summary of the executive order includes: 1) prohibits federal employers from requiring or requesting genetic tests as a condition of being hired or receiving benefits; 2) prohibits federal employers from requiring employees to undergo genetic tests in order to evaluate an employee's ability to perform his or her job; 3) prohibits federal employers from using genetic information to deprive them of advancement opportunities or overseas posts because of a genetic predisposition for certain illnesses; 4) and provides strong privacy protections to any genetic information used for medical treatment and research (*Genetics Privacy* 1).[21]

In 1996, the Oklahoma Legislature established a task force (OK HCR #113) to review Oklahoma House Bill No. 2478 that proposed the creation of a Genetic Nondiscrimination Act, and required the task force to report to the legislature by January 1, 1997. In 1997, this task force was extended (OK HCR #1012) for the continued review of Oklahoma House Bill No. 2478, and required the task force to report to the legislature by January 1, 1998. In 1998, HB 3169 was enacted for the purposes of preventing genetic discrimination in the workplace, prohibiting insurers from requiring or conditioning the provision of a policy by requiring or requesting an individual undergo genetic testing, and provides definitions of genetic information and genetic test. In 1999, HB 1368 was enacted for the purposes of protecting the confidentiality of individuals participating in research studies by prohibiting the subpoena or discovery of research records in civil suits, provides that stored tissues can be used for genetic research if informed consent has been obtained, and protects the confidentiality of individuals participating in research studies by prohibiting the publishing of a participants identification unless informed consent has been obtained.

The U.S. Congress has yet to pass comprehensive legislation addressing privacy of genetic information and health insurance discrimination. The federal laws of ADA, HIPPA, Civil Rights Act, and the Oklahoma state statutes are inadequate to protect genetic privacy and prevent discrimination. The provision of leadership and community partnerships to ensure all Oklahomans benefit from genetic medicine of today and of the future, and to monitor the state for genetic discrimination, invasion of privacy, or exploitation will be a crucial role for public health.

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[20] *Genetics Privacy Legislation...*

[21] *Genetics Privacy Legislation...*