



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
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The Honorable John Carney
Governor

John A. McNeal
Director

MEMORANDUM

DATE: February 28, 2019

TO: All Members of the Delaware State Senate
and House of Representatives

FROM: Mr. J. Todd Webb, Chairperson
State Council for Persons with Disabilities

RE: S.B. 17 (Insurance Discrimination Based on Genetic Information)

The State Council for Persons with Disabilities (SCPD) has reviewed S.B. 17 which prohibits discrimination based upon genetic characteristics and information in the issuance or renewal of disability and long term care insurance. S.B. 17 increases the protection provided by the Genetic Information Nondiscrimination Act of 2008 (GINA). GINA protects individuals from genetic discrimination in health insurance (Title I) and employment (Title II). SCPD has the following observations and one recommendation for an amendment to the proposed legislation.

Specifically, health insurers cannot use genetic information to make decisions about eligibility, coverage terms, or premiums. Health insurers may not request or require individuals to undergo genetic testing; consider family health history or a genetic test result as a pre-existing condition; or to use any genetic information they have to discriminate against the individual.

GINA does not apply to the following: federal employees who receive medical care through the Federal Employees Health Benefits Plans; members of the military who receive care through TRICARE; veterans who receive care through the Veterans Health Administration; and Native Americans who receive care through the Indian Health Service. In addition, GINA does not cover long term care insurance, life insurance, or disability insurance.

Employers cannot use family health history and genetic test results in making decisions about an individual's employment. Specifically, employers cannot use genetic information in employment decisions such as hiring, firing, promotions, pay, and job assignments. Employers are also prohibited from requesting genetic information or genetic testing as a condition of employment.

GINA provides the minimum level of protection against genetic discrimination. However, states can provide more protection against genetic discrimination. S.B. 17 is an attempt to broaden GINA to prohibit genetic discrimination in the issuance or renewal of disability insurance and long term care insurance. The bill would amend 18 Del. C. §2317. The bill provides that if an insurer requires a genetic test, notice that a test is required be given to the individual. Written authorization to perform the test is also required. The bill applies to everyone seeking disability or long term care insurance.

SCPD believes the bill has a noticeable shortcoming, namely that it does not apply to life insurance. The same arguments that have been advanced with respect to disability and long term care insurance apply equally to life insurance. If life insurance companies were prohibited from using the genetic test results of applicants, genetically at risk individuals would be more willing to have genetic testing. This could lead to earlier medical treatment, resulting in improved health and increased life expectancy of the affected individuals. Other states, including Arizona, Maine, and New Jersey, prohibit genetic discrimination for life insurance and disability insurance policies without actuarial justification. Massachusetts, Montana, and New Mexico prohibit genetic discrimination for life, disability, and long term care insurance policies. SCPD recommends an amendment to also prohibit genetic discrimination in the issuance or renewal of life insurance policies. This would give greater protection to all those individuals who want to have or are considering having genetic testing.

In addition, the Council does not support a requirement for the collection of genetic information and Council does not support the application of familial genetic information to another family member without express consent of the individual.

Thank you for your consideration and please contact SCPD if you have any questions regarding our observations on the proposed legislation.

cc: Ms. Laura Waterland, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

SB 17 insurance discrimination based on genetic info 2-28-19