HOUSE BILL REPORT
SHB 1079

As Passed House:
February 27, 2023

Title: An act relating to rapid whole genome sequencing.

Brief Description: Concerning rapid whole genome sequencing.

Sponsors: House Committee on Health Care & Wellness (originally sponsored by Representatives Thai, Slatter and Ryu).

Brief History:
Committee Activity:
Health Care & Wellness: 1/18/23, 2/1/23 [DPS].
Floor Activity:
Passed House: 2/27/23, 95-0.

Brief Summary of Substitute Bill

- Requires that medical assistance programs provide coverage for rapid whole genome sequencing for enrollees who are up to age 1 in accordance with medical necessity criteria to be adopted by the Health Care Authority.

HOUSE COMMITTEE ON HEALTH CARE & WELLNESS

Majority Report: The substitute bill be substituted therefor and the substitute bill do pass. Signed by 17 members: Representatives Riccelli, Chair; Bateman, Vice Chair; Schmick, Ranking Minority Member; Hutchins, Assistant Ranking Minority Member; Barnard, Bronoske, Davis, Graham, Harris, Macri, Maycumber, Mosbrucker, Orwall, Simmons, Stonier, Thai and Tharinger.

Staff: Christopher Blake (786-7392).

This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not part of the legislation nor does it constitute a statement of legislative intent.

Background:

Genetic Sequencing.
A genome is a human's or other organism's complete set of genetic information. The genome of a human contains between 20,000 and 25,000 genes. Each gene carries information that determines a different trait, which is a feature or characteristic that may be inherited from the parents and passed down to the offspring. The molecules that make up the genome and its genes are called deoxyribonucleic acid (DNA). The genetic information in DNA is stored as a code made up of four building blocks, or bases. A gene variant is a heritable change to the DNA sequence that makes up a gene. Most gene variants have no impact on a person's health or development, but some gene variants result in genetic diseases.

Using a method or technology called DNA sequencing, it is possible to determine whether a person has one or more variants in a single gene, multiple genes, or in the whole genome. When testing for single gene variants and analysis of one or more gene sequences does not provide a diagnosis of disease, whole genome sequencing may be used to locate rare gene variants that may be the genetic cause of the condition.

The Health Care Authority does not have an official policy on Medicaid reimbursement for payment codes related to whole genome sequencing, but will consider requests for payment according to the standards used by other payers or professional organizations.

Summary of Substitute Bill:

Beginning January 1, 2024, medical assistance programs administered by the Health Care Authority (Authority) must require provider payment for rapid whole genome sequencing for enrollees who are up to age 1. The Authority must adopt medical necessity criteria for the coverage upon consideration of standards developed by the American College of Medical Genetics and Genomics and hospitals in Washington that predominantly serve children. The term "rapid whole genome sequencing" is defined as the unbiased sequencing of all deoxyribonucleic acid bases in the genome of a patient for the purpose of determining whether one or more potentially disease-causing genetic variants are present in the genome of the patient or biological parent.

Appropriation: None.

Fiscal Note: Available.

Effective Date: The bill takes effect 90 days after adjournment of the session in which the bill is passed.

Staff Summary of Public Testimony:

(In support) One in eight Americans are affected by a rare disease and 50 percent of patients with rare diseases are children. Approximately $700 billion are spent on rare diseases every year compared to $800 billion for common conditions.

The early diagnosis and interventions in this bill are very important and studies have shown that it can save significant amounts of money. Some conditions can take seven to nine years to receive a diagnosis and this bill can reduce that time which helps patients economically, emotionally, and psychologically, as well as maintain quality of life. Time is of the essence in determining an accurate diagnosis and appropriate treatment and this bill will allow that. This bill saves lives and reduces economic impact. Until recently, health care providers had to conduct one test at a time to diagnose genetic conditions which is time consuming, costly, and not always successful in diagnosing. Rapid whole genome sequencing combines many tests into one and offers the best available diagnostic option for individuals with an undiagnosed rare disease.

Genetic counselors are highly skilled and knowledgeable and can help families understand the information that they receive and to make informed decisions. Genetic counselors are critical to assure the appropriate utilization of rapid whole genome sequencing and education regarding the test results, however there are financial and geographic barriers. Telehealth is promising and would require payment parity and reduce regulation similar to improvements seen with mental health counseling.

(Opposed) Bills with mandates should not be considered in isolation and there should be a comprehensive assessment of their effect on the overall cost of premiums. Health plans are interested in why this bill goes up to 21 years old, rather than just under one year of age, as in other states.

Persons Testifying: (In support) Representative My-Linh Thai, prime sponsor; Kari Cunningham-Rosvik; and Carolina Sommer, Jessie Conta, and Sarah Tompkins, Northwest Rare Disease Coalition.

(Opposed) Jennifer Ziegler, Association of Washington Health Care Plans.

Persons Signed In To Testify But Not Testifying: None.