H-0206.1

HOUSE BILL 1444

State of Washington 69th Legislature 2025 Regular Session

By Representatives Thai, Corry, Stonier, Bergquist, Macri, Callan, Reeves, Davis, Reed, Parshley, Salahuddin, Hill, and Tharinger

Read first time 01/21/25. Referred to Committee on Health Care & Wellness.

AN ACT Relating to rapid whole genome sequencing; adding a new section to chapter 74.09 RCW; and creating a new section.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

NEW SECTION. **Sec. 1.** The legislature finds that:

(1) 80 percent of rare diseases are genetic in origin;

(2) Half of all rare disease patients are children;

(3) 30 percent of children with a rare disease will not live to see their fifth birthday;

(4) Rapid whole genome sequencing has demonstrated significant clinical utility to increase early detection of rare diseases in children, improved health outcomes for those impacted by genetic disorders, and yielded demonstrable savings to health care systems by enabling earlier intervention;

(5) Access to the results of rapid whole genome sequencing empowers parents to join health care providers in making the most informed care decisions that can avoid other costly tests and invasive procedures, resulting in fewer days in the hospital;

(6) Rapid whole genome sequencing allows health care providers to identify the exact cause of a genetic disorder in a matter of days instead of four to six weeks in the case of other genetic testing;

(7) Access to genetic testing is more difficult to obtain for families with lower household incomes; and

(8) Time is of the essence for rare disease families and their loved ones seeking accurate diagnoses and medically appropriate treatments.

NEW SECTION. **Sec. 2.** A new section is added to chapter 74.09 RCW to read as follows:

(1) Beginning January 1, 2026, the authority must require provider payment for rapid whole genome sequencing, including pretest counseling and posttest counseling by an appropriate health care provider, for enrollees in medical assistance programs up to one year of age receiving inpatient hospital services in an intensive care unit or neonatal or high acuity pediatric care unit if the following conditions are met:

(a) The medical condition of the enrollee's features is not known and the enrollee's phenotype includes one or more of the following:

(i) Multiple congenital abnormalities affecting unrelated organ systems;

(ii) A specific abnormality affecting at least one organ system that is highly suggestive of a genetic condition;

(iii) Epilepsy of an unexplained cause with early onset;

(iv) Symptoms of a complex neurological condition;

(v) Cardiac diagnostic testing suggestive of possible channelopathies, arrythmias, cardiomyopathies, myocarditis, or structural heart disease;

(vi) Laboratory findings that suggest a genetic condition or inherited metabolic disorder; or

(vii) Abnormal response to standard therapy;

(b) Alternate causes have been considered and determined not to be the cause of the illness; and

(c) Timely identification of a molecular diagnosis is necessary to guide clinical decision making and results of rapid whole genome sequencing may aid in guiding the treatment or management of a condition.

(2) If the authority or a managed care organization uses a capitated or bundled payment arrangement to reimburse a health care provider for services provided to an enrollee in an inpatient setting, reimbursement for services covered by this section must be paid separately and in addition to any reimbursement otherwise

payable to the health care provider under the capitated or bundled payment arrangement, unless the authority or managed care organization and the health care provider have negotiated an increased capitated or bundled payment rate to include rapid whole genome sequencing, as provided under this section.

(3) For the purposes of this section, "rapid whole genome sequencing" means an investigation of the entire human genome, including coding and noncoding regions and mitochondrial deoxyribonucleic acid, to identify disease-causing genetic changes where a final report is delivered in less than 14 days. "Rapid whole genome sequencing" includes patient-only whole genome sequencing, as well as duo and trio whole genome sequencing of the patient and the patient's biological parent or parents. "Rapid whole genome sequencing" includes any analysis, interpretation, and data report derived from such sequencing.

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