Substitute House Bill No. 5367

Public Act No. 24-130

AN ACT CONCERNING MEDICAID COVERAGE OF RAPID WHOLE GENOME SEQUENCING FOR CRITICALLY ILL INFANTS AND STUDIES CONCERNING THE ELIMINATION OR REDUCTION OF THE KATIE BECKETT WAIVER PROGRAM WAITING LIST AND MEDICAID COVERAGE OF DIAPERS.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (*Effective July 1, 2024*) (a) As used in this section, (1) "rapid whole genome sequencing" means a test designed to diagnose genetic disorders in time to inform or change acute medical or surgical management of a critically ill infant, and (2) "infant" means a child from birth to age twelve months. The Commissioner of Social Services shall, within available appropriations, provide medically necessary Medicaid coverage for rapid whole genome sequencing of a critically ill infant enrolled in the Medicaid program who is being treated in a neonatal intensive care or pediatric intensive care unit.

(b) The commissioner shall require that any health care provider receiving reimbursement for such test certify, in writing, that any genetic data resulting from such test is (1) used only to assist in diagnosing and treating the infant, (2) protected in accordance with the federal Health Insurance Portability and Accountability Act of 1996, P.L. 104-191, as amended from time to time, and (3) not used in scientific research unless a parent or legal guardian of the infant expressly

consents to such use.

(c) The commissioner shall take actions necessary to implement the provisions of this section, including, but not limited to, (1) promulgating regulations in accordance with chapter 54 of the general statutes to provide payment for such rapid whole genome sequencing, and (2) submitting to the Centers for Medicare and Medicaid Services any new waiver application, amendment to an existing waiver or Medicaid state plan amendment necessary to ensure federal financial participation for Medicaid coverage of such rapid whole genome sequencing.

(d) In developing regulations pursuant to subsection (c) of this section, the commissioner shall establish evidence-based medical necessity criteria for such rapid whole genome sequencing coverage that shall include, but need not be limited to: (1) The infant has symptoms that suggest a broad differential diagnosis that would require an evaluation by multiple genetic tests if rapid whole genome sequencing is not performed, (2) the infant's treating health care provider has provided a written determination that rapid whole genome sequencing is necessary to guide clinical decision making, and (3) the infant has complex or acute illness of unknown etiology, which may include (A) congenital anomalies involving at least two organ systems or complex or multiple congenital anomalies in one organ system, (B) specific organ malformations highly suggestive of a genetic etiology, or (C) abnormal laboratory tests or abnormal chemistry profiles suggesting the presence of a genetic disease.

Sec. 2. (*Effective July 1, 2024*) (a) As used in this section, (1) "Katie Beckett Waiver Program" means the waiver program for children and young adults with disabilities established pursuant to section 17b-283 of the general statutes, (2) "rare disease" means a disease or condition affecting fewer than two hundred thousand persons in the United States, (3) "extremely rare disease" means a disease affecting fewer than five thousand people in the United States, as such diseases are recorded

by the Genetic and Rare Diseases Information Center of the National Institutes of Health, and (4) "terminal illness" means an illness or condition that is incurable and can lead to death.

(b) The House and Senate chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to human services shall appoint a working group to study and make recommendations concerning eliminating or reducing the waiting list for services in the Katie Beckett Waiver Program and establishing priority placements on such list based on illness and life expectancy.

(c) Said chairpersons shall convene the first meeting of the working group not later than August 1, 2024. The working group shall consist of:

(1) The House and Senate chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to human services, or their designees, who shall serve as chairpersons of the working group;

(2) The ranking House and Senate members of the joint standing committee of the General Assembly having cognizance of matters relating to human services, or their designees;

(3) The following members appointed by the House and Senate chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to human services:

(A) One parent or legal guardian of a child on the waiting list with an extremely rare disease that is a terminal illness;

(B) One parent or legal guardian of a child on the waiting list with a rare disease that is a terminal illness;

(C) One young adult on the waiting list with a rare disease, terminal illness or both, or such young adult's parent or legal guardian;

(D) One representative of the Connecticut Children's Medical Center with expertise in pediatric rare genetic diseases or medical treatments for terminal illness;

(E) One representative of The University of Connecticut Health Center's Department of Pediatrics with expertise in pediatric rare genetic diseases or terminal illness research;

(F) One representative of the Yale School of Medicine's Department of Pediatrics; and

(G) One representative of the Connecticut Rare Disease Advisory Council;

(4) The Commissioner of Social Services, or the commissioner's designee; and

(5) The Secretary of the Office of Policy and Management, or the secretary's designee.

(d) The working group shall:

(1) Develop a strategy to eliminate the waiting list for services and an alternate strategy to reduce the waiting list, with estimated state costs;

(2) Develop a model for how the Department of Social Services could track children and young adults on the waiting list by type of disease or disability and life expectancy;

(3) Estimate costs to implement such tracking model and amount of time needed to implement such model;

(4) Recommend statutory definitions for terminal illness, limited life expectancy and other terms deemed appropriate for use by the working group in the establishment of any priority tier on the waiting list for services in the waiver program;

(5) Determine average life expectancy associated with certain rare diseases and extremely rare diseases;

(6) (A) Analyze models in other states for offering similar services to those offered by the Katie Beckett Waiver Program, (B) determine whether and how other states establish priority placements for such services, and (C) estimate costs to adopt any such models or priority placement programs in this state;

(7) Determine to what extent the waiver program is serving all eligible persons in the state and, if necessary, develop a public awareness strategy to increase participation to the estimated capacity of the program in the future; and

(8) Develop protocols to ensure the protection of private health information of participants in the waiver program and those on the waiting list for such program in accordance with state and federal law.

(e) The administrative staff of the joint standing committee of the General Assembly having cognizance of matters relating to human services shall provide administrative support to the working group.

(f) Not later than February 15, 2025, the working group shall submit a report, in accordance with the provisions of section 11-4a of the general statutes, to the joint standing committees of the General Assembly having cognizance of matters relating to appropriations and human services on the results of the study and the working group's recommendations. The working group shall terminate on the date the report is submitted, or February 15, 2025, whichever is earlier.

Sec. 3. (*Effective from passage*) (a) The Commissioner of Social Services shall study the feasibility of expanding Medicaid coverage for diapers to children from birth to age three for whom diapers are medically necessary in accordance with section 17b-259b of the general statutes.

(b) Not later than January 1, 2025, the commissioner shall file a report on the study, in accordance with the provisions of section 11-4a of the general statutes, with the joint standing committee of the General Assembly having cognizance of matters relating to human services. The report shall include, but need not be limited to, analysis of and recommendations concerning: (1) Federal requirements for Medicaid coverage of diapers for such children, (2) a summary of diaper coverage under Medicaid programs in other states, (3) clinical best practices, (4) operational and programmatic considerations, (5) opportunities to utilize the existing diaper coverage system for certain Medicaid recipients, (6) coverage options, and (7) fiscal impact to the state.