PA 24-130—sHB 5367
Human Services Committee
Appropriations Committee

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

SUMMARY: This act requires the Department of Social Services (DSS) commissioner to provide medically necessary Medicaid coverage for rapid whole genome sequencing for certain critically ill infants, within available appropriations. These are tests for diagnosing genetic disorders in time to inform or change acute medical or surgical management of critically ill infants. The coverage requirement applies to infants ages 0 to 12 months who are enrolled in Medicaid and being treated in neonatal or pediatric intensive care units.

The act also requires the Human Services Committee chairpersons to establish a working group to study and make recommendations on reducing or eliminating the waitlist for the Katie Beckett waiver and establishing priority placements on the list based on illness and life expectancy. The Katie Beckett waiver provides Medicaid coverage for children and young adults with disabilities.

Lastly, the act requires the DSS commissioner to study the feasibility of providing Medicaid coverage for diapers to children ages birth to three for whom diapers are medically necessary. She must report her findings to the Human Services Committee by January 1, 2025.

EFFECTIVE DATE: July 1, 2024, except the diaper study requirement is effective upon passage.

§ 1 — RAPID WHOLE GENOME SEQUENCING

Test Data Requirements

Under the act, the DSS commissioner must require that providers receiving payments for rapid whole genome sequencing certify in writing that any genetic data resulting from a test is:

1. used only to help diagnose and treat the infant;
2. protected under the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA); and
3. not used in scientific research unless the infant's parent or legal guardian expressly consents.

Regulations, Waivers, and State Plan Amendments

The act requires the DSS commissioner to take actions needed to implement these provisions, including (1) adopting regulations on provider payments and (2) submitting any Medicaid waiver applications and amendments or state plan amendments to the Centers for Medicare and Medicaid Services to ensure federal matching funds for this coverage.

Medical Necessity Criteria

The act requires the DSS commissioner, when developing regulations for provider payments, to set evidence-based medical necessity criteria. These criteria must include at least the following:

1. the infant has symptoms suggesting a broad differential diagnosis that would require an evaluation by multiple genetic tests if rapid whole genome sequencing is not used,
2. the infant's treating health care provider gave a written determination that rapid whole genome sequencing is needed to guide clinical decision making, and
3. the infant has complex or acute illness of unknown cause.

These complex or acute illnesses may include (1) congenital anomalies involving at least two organ systems or complex or multiple congenital anomalies in one organ system, (2) specific organ malformations highly suggesting a genetic cause, or (3) abnormal lab tests or abnormal chemistry profiles that suggest a genetic disease.

Existing law, unchanged by the act, sets separate standards for medically necessary services in DSS's medical assistance programs, including Medicaid.

§ 2 — KATIE BECKETT WAITLIST WORKING GROUP

The act requires the working group to do the following;

1. develop a strategy to eliminate the waiting list for services and an alternate strategy to reduce the waiting list, with estimated costs;
2. develop a model for how DSS could track children and young adults on the waitlist by type of disease or disability and life expectancy;
3. estimate costs and amount of time needed to implement the tracking model;
4. recommend statutory definitions for terminal illness, limited life expectancy, and other terms deemed appropriate for the working group's use when setting any priority tier on the waitlist;
5. determine average life expectancy associated with certain rare diseases and extremely rare diseases;
6. analyze other states' models for offering similar services to those offered under the Katie Beckett waiver, determining whether and how they establish priority placements for services, and estimate costs to adopt these models or priority placement processes in Connecticut;

7. determine the extent to which the waiver program is serving all eligible people in the state and, if needed, develop a public awareness strategy to increase participation to the program's estimated future capacity; and
8. develop protocols to ensure private health information is protected for waiver participants and people on the waitlist in accordance with state and federal law.

Membership and Report

The working group includes the Human Services Committee chairpersons and ranking members, the DSS commissioner, and the Office of Policy and Management secretary, or their designees, and the following members, appointed by the Human Services Committee chairpersons:

1. two parents or legal guardians of children on the waitlist with terminal illnesses, one with a child with a rare disease (affecting fewer than 200,000 people in the United States) and one with a child with an extremely rare disease (affecting fewer than 5,000 people in the United States, as recorded by the National Institutes of Health's Genetic and Rare Diseases Information Center);
2. one young adult on the waitlist with a rare disease, terminal illness, or both, or the young adult's parent or legal guardian;
3. one Connecticut Children's Medical Center representative with expertise in pediatric rare genetic diseases or medical treatments for terminal illness;
4. one UConn Health Center Department of Pediatrics representative with expertise in pediatric rare genetic diseases or terminal illness research;
5. one representative from Yale School of Medicine's Department of Pediatrics; and
6. one Connecticut Rare Disease Advisory Council representative.

The Human Services Committee chairpersons, or their designees, serve as the working group's chairpersons and must convene its first meeting by August 1, 2024. The Human Services Committee's administrative staff serve in this capacity for the working group.

Under the act, the working group must report its findings and recommendations to the Appropriations and Human Services committees by February 15, 2025. It terminates on that date or whenever it submits its report, whichever is sooner.

§ 3 — STUDY ON MEDICAID COVERAGE FOR DIAPERS

The act requires the DSS commissioner to study the feasibility of expanding Medicaid coverage for diapers to children ages birth to three for whom diapers are medically necessary. The act requires the commissioner to report her findings to the Human Services Committee by January 1, 2025. The report must analyze and make recommendations on the following topics:

1. federal requirements for Medicaid coverage of diapers for children described above,

2. a summary of diaper coverage under Medicaid programs in other states,
3. clinical best practices,
4. operational and programmatic considerations,
5. opportunities to use the existing diaper coverage system for certain Medicaid recipients,
6. coverage options, and
7. the fiscal impact to the state.

BACKGROUND

Related Act

PA 24-50 requires DSS to provide Medicaid coverage for biomarker testing, which, under the act, includes whole genome sequencing.