

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2023

FILED SENATE
Apr 3, 2023
S.B. 466
PRINCIPAL CLERK

S

D

SENATE BILL DRS35181-MR-33

Short Title: Help Medically Complex Children.

(Public)

Sponsors: Senators Perry and Lee (Primary Sponsors).

Referred to:

1 A BILL TO BE ENTITLED
2 AN ACT TO PROVIDE COVERAGE OF COMPREHENSIVE GENOMIC TESTING TO
3 MEDICAID BENEFICIARIES TWENTY-ONE YEARS OLD OR YOUNGER
4 EXPERIENCING CERTAIN ACUTE OR COMPLEX ILLNESSES.

5 Whereas, children with medical complexity have at least one chronic condition,
6 technology dependence, multiple subspecialist involvement, and substantial healthcare use; and

7 Whereas, although these children with medical complexity compose less than one
8 percent (1%) of the pediatric population, they account for thirty-three percent (33%) of all
9 pediatric health care spending; and

10 Whereas, a genetic cause is suspected in a large proportion of children with medical
11 complexity, but most remain undiagnosed with conventional genetic testing; and

12 Whereas, for many families, the diagnostic process is time intensive, resource
13 intensive, and emotionally intensive; Now, therefore,
14 The General Assembly of North Carolina enacts:

15 **SECTION 1.** The Department of Health and Human Services, Division of Health
16 Benefits (DHB), shall seek the necessary approval from the Centers for Medicare and Medicaid
17 Services (CMS) to draw down a federal Medicaid match for coverage of comprehensive genomic
18 testing, including rapid whole genome sequencing, for Medicaid beneficiaries 21 years old or
19 younger. For the purposes of this coverage, all of the following shall apply:

- 20 (1) The beneficiary is experiencing an acute or complex illness of unknown
21 etiology that has not been confirmed to be caused by an environmental
22 exposure, ingestion of a toxic substance, an infection with normal response to
23 therapy, or trauma.
- 24 (2) The beneficiary is receiving inpatient hospital services in an intensive care
25 unit or a high acuity pediatric care unit.
- 26 (3) Rapid whole genome sequencing shall be included. Rapid whole genome
27 sequencing is the investigation of the entire human genome, including coding
28 and non-coding regions and mitochondrial deoxyribonucleic acid, to identify
29 disease-causing genetic changes and that returns (i) preliminary positive
30 results within five days of the sample being taken and (ii) final results within
31 14 days of the sample being taken.
- 32 (4) Coverage includes beneficiary-only whole genome sequencing and duo and
33 trio whole genome sequencing of the beneficiary experiencing the acute or
34 complex illness and any biological parent of that beneficiary, whether the
35 parent is a Medicaid beneficiary or not.



- 1 (5) Coverage shall begin on the effective date approved by CMS and shall be
2 implemented to the extent approved by CMS.
- 3 (6) Genetic data generated as a result of the covered testing shall have the primary
4 use of assisting the beneficiary's healthcare providers in the diagnosis and
5 treatment of the beneficiary. The federal Health Information Portability and
6 Accountability Act (HIPAA) shall apply to all data collected. This genetic
7 data may be used in scientific research if consent for that use has been
8 expressly given by the beneficiary or the beneficiary's legal guardian, as
9 applicable.
- 10 (7) Access to the results of the comprehensive genomic testing shall be made
11 available upon request to the beneficiary, any biological parent of the
12 beneficiary, or the beneficiary's legal guardian.
- 13 (8) Coverage shall begin on the date approved by CMS but shall begin no sooner
14 than July 1, 2023.

15 **SECTION 2.** Effective July 1, 2023, there is appropriated from the General Fund to
16 the Department of Health and Human Services, Division of Health Benefits, the sum of five
17 hundred thousand dollars (\$500,000) in recurring funds for the 2023-2024 fiscal year and the
18 sum of five hundred thousand dollars (\$500,000) in recurring funds for the 2024-2025 fiscal year
19 to implement the Medicaid coverage described under Section 1 of this act. These funds shall
20 provide a State match for nine hundred sixty-seven thousand dollars (\$967,000) in recurring
21 federal funds for the 2023-2024 fiscal year and nine hundred sixty-seven thousand dollars
22 (\$967,000) in recurring federal funds for the 2024-2025 fiscal year. Those federal funds are
23 appropriated to the Division of Health Benefits to pay for costs associated with the Medicaid
24 coverage described under Section 1 of this act.

25 **SECTION 3.** This act is effective when it becomes law.