

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2023

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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.