119TH CONGRESS
2D SESSION

S. _____

To amend title XIX of the Social Security Act to clarify that whole genome and whole exome sequencing for children with certain medical needs is covered under the Medicaid program.

IN THE SENATE OF THE UNITED STATES

Mr. WICKER (for himself, Ms. KLOBUCHAR, Mr. SCHMITT, and Mr. COONS) introduced the following bill; which was read twice and referred to the Committee on _____

A BILL

To amend title XIX of the Social Security Act to clarify that whole genome and whole exome sequencing for children with certain medical needs is covered under the Medicaid program.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Genomic Answers for Children's Health Act of 2026''.

SEC. 2. CLARIFYING THAT WHOLE GENOME AND WHOLE EXOME SEQUENCING FOR CHILDREN WITH CERTAIN MEDICAL NEEDS IS COVERED UNDER THE MEDICAID PROGRAM.

(a) IN GENERAL.—Section 1905 of the Social Security Act (42 U.S.C. 1396d) is amended—

(1) in subsection (r)—

(A) by redesignating paragraph (5) as paragraph (6); and

(B) by inserting after paragraph (4) the following new paragraph:

''(5) Whole genome sequencing and whole exome sequencing (as defined in subsection (ll)), whether furnished in the inpatient or outpatient setting, if ordered by a physician or other provider acting within the provider's scope of practice under State law as a first-tier test for an individual suspected to have a genetic disorder, rare disease, or a health condition of unknown origin, including 1 or more congenital anomalies, a global developmental delay, or an intellectual disability.''; and

(2) by adding at the end the following new subsection:

''(ll) WHOLE GENOME SEQUENCING AND WHOLE EXOME SEQUENCING.—For purposes of subsection (r)(5),

the term 'whole genome sequencing and whole exome sequencing'—

''(1) means the determination of a sequence of deoxyribonucleic acid bases in the genome taken or derived from an individual, and, if for the primary benefit of the individual's diagnosis or treatment, a first degree biological relative or relatives of such individual for the purpose of determining whether 1 or more potentially disease-causing genetic variants are present in the genome of such individual or such biological first-degree relative; and

''(2) includes—

''(A) the sequencing of the whole genome or the whole exome; and

''(B) any analysis, interpretation, and data report derived from such sequencing.''.

(b) ADDITIONAL UPDATES.—Section 1902(a) of the Social Security Act (42 U.S.C. 1396a(a)) is amended—

(1) in paragraph (89), by striking ''and'' at the end;

(2) in paragraph (90), by striking the period and inserting ''; and''; and

(3) by inserting after paragraph (90) the following new paragraph:

''(91) provide that payment for whole genome sequencing and whole exome sequencing (as defined in section 1905(ll)) is made separately and is not bundled as part of payment for any other medical assistance.''.

(c) OUTREACH AND EDUCATION.—For purposes of promoting awareness of and access to whole genome and exome sequencing under section 1905(r) of the Social Security Act (42 U.S.C. 1396d(r)), the Secretary of Health and Human Services shall—

(1) convene national organizations (including at least those organizations representing pediatricians, specialists in pediatric rare diseases, children's hospitals, geneticists, genetic counselors, laboratory test developers), States, hospitals and health systems, individuals with rare diseases, and those national organizations representing Medicaid managed care organizations to identify challenges and opportunities in implementation of the amendments made by this section, including potential best practices that minimize denials of claims for medical assistance under the State plan under title XIX of such Act resulting from use of prior authorization or administrative requirements.

(2) conduct outreach to national organizations (including at least those organizations representing hospitals, health systems, children's hospitals, pediatricians, and geneticists), States, national organizations representing Medicaid managed care organizations, national organizations representing rare disease patients and families, and national organizations representing Medicaid-eligible children and their families to ensure they are aware of the early and periodic screening, diagnostic, and treatment services benefit under title XIX of such Act and can benefit from access to required screenings and necessary treatment services; and

(3) not later than 2 years after the date of the enactment of this Act, publish on the public website of the Department of Health and Human Services a report that includes—

(A) payment amounts for whole genome sequencing and whole exome sequencing under each State plan under title XIX of such Act; and

(B) information relating to the number of children receiving such sequencing under such State plans, health outcomes, types of services

provided as a result of such sequencing, and other such relevant information.

(d) REPORT.—Not later than 2 years after the date of the enactment of this Act, the Comptroller General of the United States shall do the following:

(1) Collect and analyze feedback regarding implementation of the amendments made by this Act from the organizations and entities described in paragraph (1) or (2) of subsection (c), including—

(A) experiences in accessing whole genome sequencing and whole exome sequencing and results pursuant to such amendments, including any barriers to such access;

(B) changes to care or services furnished after such sequencing;

(C) identification of remaining challenges, if any, related to access to such sequencing for individuals eligible for early and periodic screening, diagnostic, and treatment services under the Medicaid program; and

(D) health professional awareness of such amendments.

(2) Assess the following for impacts on access to such sequencing under such program for such individuals:

(A) Prior authorization, which may include assessment of impacts related to delay of care and uncertainty or surprise of payment.

(B) Workforce and reimbursement challenges for genetic counselors.

(C) The extent to which market cost is aligned with the Medicare clinical laboratory fee schedule and the degree to which the Secretary of Health and Human Services' adjustment of the fee schedule might more accurately reflect market realities and support affordability.

(3) Make recommendations to the Secretary of Health and Human Services relating to additional guidance or improvements that may be made based on the feedback collected under paragraph (1) and the assessment described in paragraph (2).

(e) EFFECTIVE DATE.—

(1) IN GENERAL.—Subject to paragraph (2), the amendments made by subsections (a) and (b) shall apply with respect to medical assistance provided on or after January 1, 2027.

(2) EXCEPTION FOR STATE LEGISLATION.—In the case of a State plan under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) that the Secretary of Health and Human Services determines

requires State legislation in order for such plan to meet any requirement imposed by the amendments made by this section, such plan shall not be regarded as failing to comply with the requirements of such title solely on the basis of its failure to meet such an additional requirement before the first day of the first calendar quarter beginning after the close of the first regular session of the State legislature that begins after the date of the enactment of this Act. For purposes of the previous sentence, in the case of a State that has a 2-year legislative session, each year of the session shall be considered to be a separate regular session of the State legislature.