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119TH CONGRESS
1ST SESSION

H. R. 5178

To amend title XIX of the Social Security Act to enable State Medicaid programs to provide comprehensive, coordinated care through a health home to individuals with sickle cell disease.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 8, 2025

Mr. DUNN of Florida (for himself, Mr. DAVIS of Illinois, Mr. CARTER of Georgia, Mr. FIGURES, Mr. BILIRAKIS, Ms. JOHNSON of Texas, Ms. NORTON, Mrs. MCIVER, Mr. FIELDS, Mr. GREEN of Texas, Mr. GOTTHEIMER, Ms. TLAIB, Mr. JOHNSON of Georgia, Mr. JACKSON of Illinois, Mr. DAVIS of North Carolina, Mr. SOTO, Ms. BUDZINSKI, Ms. SEWELL, Mr. THOMPSON of Mississippi, and Mr. MOULTON) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To amend title XIX of the Social Security Act to enable State Medicaid programs to provide comprehensive, coordinated care through a health home to individuals with sickle cell disease.

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 ''Sickle Cell Disease Comprehensive Care Act''.

SEC. 2. ENABLING STATE MEDICAID PROGRAMS TO PROVIDE CARE THROUGH HEALTH HOMES TO INDIVIDUALS WITH SICKLE CELL DISEASE.

Section 1945 of the Social Security Act (42 U.S.C. 1396w–4) is amended—

(1) in subsection (a), by inserting ''(and, beginning January 1, 2026, to eligible individuals with sickle cell disease (as defined in subsection (c)(5)))'' after ''chronic conditions'';

(2) in subsection (c)—

(A) in paragraph (1), by inserting ''and each eligible individual with sickle cell disease'' after ''chronic conditions''; and

(B) by adding at the end the following new paragraph:

''(5) SPECIAL RULE RELATING TO SICKLE CELL DISEASE HEALTH HOMES.—

''(A) IN GENERAL.—Beginning January 1, 2026, the Secretary may approve a State plan amendment under this section that is designed to provide health home services primarily to eligible individuals with sickle cell disease (in this section referred to as a 'sickle cell disease-focused State plan amendment').

''(B) REQUIREMENT TO PROVIDE DENTAL AND VISION SERVICES.—In the case of a sickle

cell disease-focused State plan amendment approved by the Secretary on or after January 1, 2026, a State shall ensure the provision of dental and vision services to eligible individuals with sickle cell disease who are enrolled in such health home. Such requirement shall apply irrespective of existing requirements related to comparability or whether or not the State provides dental or vision services to other Medicaid beneficiaries.

''(C) REPORT REQUIREMENTS.—

''(i) IN GENERAL.—In the case of a State with a sickle cell disease-focused State plan amendment, such State shall, not later than the last day of the 8th fiscal year quarter that such State plan amendment is in effect, submit to the Secretary a report on the following, with respect to eligible individuals with sickle cell disease provided health home services under such State plan amendment:

''(I) The quality of health care provided to such individuals, with a focus on outcomes relevant to the recovery of each such individual.

"(II) The access of such individuals to health care.

"(III) The total expenditures of such individuals for health care.

"(ii) APPLICABLE MEASURES.—For purposes of the report required under this subparagraph, the Secretary shall specify all applicable measures for determining quality of health care provided to eligible individuals with sickle cell disease, access to health care by such individuals, and expenditures on health care by such individuals.

"(D) BEST PRACTICES.—Not later than June 30, 2026, the Secretary shall make publicly available on the website of the Centers for Medicare & Medicaid Services best practices for designing and implementing a sickle cell disease-focused State plan amendment, based on clinical practice guidelines for sickle cell disease developed by medical specialty societies and in consultation with sickle cell disease providers and patient advocacy organizations.

"(E) DEFINITIONS.—For purposes of this section:

''(i) ELIGIBLE INDIVIDUAL WITH SICKLE CELL DISEASE.—The term 'eligible individual with sickle cell disease' means, with respect to a State, an individual who satisfies all of the following:

''(I) The individual is eligible for medical assistance under the State plan of such State or under a waiver of such plan.

''(II) The individual has sickle cell disease.

''(III) The individual may or may not have previously received health home services under any other State plan amendment approved for the State under this section by the Secretary.

''(ii) SICKLE CELL DISEASE.—The term 'sickle cell disease' means an inherited blood disorder affecting red blood cells that occurs when an individual has inherited a sickle cell gene from each parent, as identified by a newborn screening or other genetic test.''; and

(3) in subsection (h)(5), by inserting ''or a health home for eligible individuals with sickle cell disease'' after ''chronic conditions''.

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