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(Original Signature of Member)

118TH CONGRESS
2D SESSION

H. R.

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

Mr. BURGESS introduced the following bill; which was referred to the Committee on

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.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Sick Cell Disease Com-
5 prehensive Care Act”.

1 **SEC. 2. ENABLING STATE MEDICAID PROGRAMS TO PRO-**
2 **VIDE CARE THROUGH HEALTH HOMES TO IN-**
3 **DIVIDUALS WITH SICKLE CELL DISEASE.**

4 Section 1945 of the Social Security Act (42 U.S.C.
5 1396w-4) is amended—

6 (1) in subsection (a), by inserting “(and, begin-
7 ning January 1, 2025, to eligible individuals with
8 sickle cell disease (as described under subsection
9 (c)(5)))” after “chronic conditions”; and

10 (2) in subsection (c)—

11 (A) in paragraph (1), by inserting “and
12 each eligible individual with sickle cell disease”
13 after “chronic conditions”; and

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

16 “(5) SPECIAL RULE RELATING TO SICKLE CELL
17 DISEASE HEALTH HOMES.—

18 “(A) IN GENERAL.—Beginning January 1,
19 2025, the Secretary may approve a State plan
20 amendment under this section that is designed
21 to provide health home services primarily to eli-
22 gible individuals with sickle cell disease (in this
23 section referred to as a ‘sickle cell disease-fo-
24 cused State plan amendment’).

25 “(B) REPORT REQUIREMENTS.—In the
26 case of a State with a sickle cell disease-focused

1 State plan amendment, such State shall, at the
2 end of the first 8 fiscal year quarters that such
3 State plan amendment is in effect, submit to
4 the Secretary a report on the following, with re-
5 spect to eligible individuals with sickle cell dis-
6 ease provided health home services under such
7 State plan amendment:

8 “(i) The quality of health care pro-
9 vided to such individuals, with a focus on
10 outcomes relevant to the recovery of each
11 such individual.

12 “(ii) The access of such individuals to
13 health care.

14 “(iii) The total expenditures of such
15 individuals for health care.

16 For purposes of this subparagraph, the Sec-
17 retary shall specify all applicable measures for
18 determining quality, access, and expenditures.

19 “(C) BEST PRACTICES.—Not later than
20 June 30, 2025, the Secretary shall make pub-
21 licly available on the internet website of the
22 Centers for Medicare & Medicaid Services best
23 practices for designing and implementing a
24 sickle cell disease-focused State plan amend-
25 ment, based on clinical practice guidelines for

1 sickle cell diseases developed by medical spe-
2 cialty societies and in consultation with sickle
3 cell disease providers and patient advocacy or-
4 ganizations.

5 “(D) DEFINITIONS.—For purposes of this
6 section:

7 “(i) ELIGIBLE INDIVIDUAL WITH
8 SICKLE CELL DISEASE.—The term ‘eligible
9 individual with sickle cell disease’ means,
10 with respect to a State, an individual who
11 satisfies all of the following:

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

15 “(II) The individual has sickle
16 cell disease.

17 “(III) The individual may or may
18 not have previously received health
19 home services under any other State
20 plan amendment approved for the
21 State under this section by the Sec-
22 retary.

23 “(ii) SICKLE CELL DISEASE.—The
24 term ‘sickle cell disease’ means an inher-
25 ited blood disorder affecting red blood cells

1 that occurs when an individual has inher-
2 ited a sickle cell gene from each parent, as
3 identified by a newborn screening or other
4 genetic test.”; and

5 (3) in subsection (h)—

6 (A) in paragraph (4)(A)—

7 (i) by striking the period at the end
8 and inserting “; and”;

9 (ii) by striking “means comprehen-
10 sive” and inserting “means—

11 “(i) with respect to eligible individuals
12 with chronic conditions, comprehensive”;
13 and

14 (iii) by adding at the end the fol-
15 lowing new clause:

16 “(ii) in the case of a State that pro-
17 vides for dental services and vision services
18 (as defined by such State), with respect to
19 eligible individuals with sickle cell disease,
20 the services described in clause (i), dental
21 services, and vision services.”; and

22 (B) in paragraph (5), by inserting “or a
23 health home for eligible individuals with sickle
24 cell disease” after “chronic conditions”.