

118TH CONGRESS
2D SESSION

S. 5097

To amend title XIX of the Social Security Act to establish a demonstration project to improve outpatient clinical care for individuals with sickle cell disease.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 18, 2024

Mr. BOOKER (for himself, Mr. SCOTT of South Carolina, and Mr. CASSIDY) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend title XIX of the Social Security Act to establish a demonstration project to improve outpatient clinical care for 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 “Sickle Cell Disease
5 Comprehensive 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 defined in subsection (c)(5)))”
 9 after “chronic conditions”;

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

1 cell disease-focused State plan amendment ap-
2 proved by the Secretary on or after January 1,
3 2025, a State shall ensure the provision of den-
4 tal and vision services to eligible individuals
5 with sickle cell disease who are enrolled in such
6 health home. Such requirement shall apply irre-
7 spective of existing requirements related to
8 comparability or whether or not the State pro-
9 vides dental or vision services to other Medicaid
10 beneficiaries.

11 “(C) REPORT REQUIREMENTS.—

12 “(i) IN GENERAL.—In the case of a
13 State with a sickle cell disease-focused
14 State plan amendment, such State shall, at
15 the end of the first 8 fiscal year quarters
16 that such State plan amendment is in ef-
17 fect, submit to the Secretary a report on
18 the following, with respect to eligible indi-
19 viduals with sickle cell disease provided
20 health home services under such State plan
21 amendment:

22 “(I) The quality of health care
23 provided to such individuals, with a
24 focus on outcomes relevant to the re-
25 covery of each such individual.

1 “(II) The access of such individ-
2 uals to health care.

3 “(III) The total expenditures of
4 such individuals for health care.

5 “(ii) APPLICABLE MEASURES.—For
6 purposes of the report required under this
7 subparagraph, the Secretary shall specify
8 all applicable measures for determining
9 quality of health care provided to eligible
10 individuals with sickle cell disease, access
11 to health care by such individuals, and ex-
12 penditures on health care by such individ-
13 uals.

14 “(D) BEST PRACTICES.—Not later than
15 June 30, 2025, the Secretary shall make pub-
16 licly available on the website of the Centers for
17 Medicare & Medicaid Services best practices for
18 designing and implementing a sickle cell dis-
19 ease-focused State plan amendment, based on
20 clinical practice guidelines for sickle cell disease
21 developed by medical specialty societies and in
22 consultation with sickle cell disease providers
23 and patient advocacy organizations.

24 “(E) DEFINITIONS.—For purposes of this
25 section:

1 “(i) ELIGIBLE INDIVIDUAL WITH
2 SICKLE CELL DISEASE.—The term ‘eligible
3 individual with sickle cell disease’ means,
4 with respect to a State, an individual who
5 satisfies all of the following:

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

9 “(II) The individual has sickle
10 cell disease.

11 “(III) The individual may or may
12 not have previously received health
13 home services under any other State
14 plan amendment approved for the
15 State under this section by the Sec-
16 retary.

17 “(ii) SICKLE CELL DISEASE.—The
18 term ‘sickle cell disease’ means an inher-
19 ited blood disorder affecting red blood cells
20 that occurs when an individual has inher-
21 ited a sickle cell gene from each parent, as
22 identified by a newborn screening or other
23 genetic test.”; and

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

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