

119TH CONGRESS  
1ST SESSION

# S. 721

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.

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## IN THE SENATE OF THE UNITED STATES

FEBRUARY 25, 2025

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

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## 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, 2026, 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 2026, 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 2026, 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, 2026, 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:

“(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 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

- 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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