

118TH CONGRESS  
1ST SESSION

# S. 996

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

MARCH 28, 2023

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. MEDICAID DEMONSTRATION PROJECT TO IMPROVE**  
2 **OUTPATIENT CLINICAL CARE FOR INDIVID-**  
3 **UALS WITH SICKLE CELL DISEASE.**

4 Section 1903 of the Social Security Act (42 U.S.C.  
5 1396b) is amended by adding at the end the following new  
6 subsection:

7 “(cc) DEMONSTRATION PROJECT TO IMPROVE OUT-  
8 PATIENT CLINICAL CARE FOR INDIVIDUALS WITH SICKLE  
9 CELL DISEASE.—

10 “(1) IN GENERAL.—Notwithstanding section  
11 1902(a)(1) (relating to statewideness), section  
12 1902(a)(10)(B) (relating to comparability), and any  
13 other provision of this title for which the Secretary  
14 determines it is necessary to waive in order to imple-  
15 ment this subsection, not later than the date that is  
16 1 year after the date of the enactment of this sub-  
17 section, the Secretary shall, in consultation, as ap-  
18 propriate, with the Administrator of the Health Re-  
19 sources and Services Administration, the Director of  
20 the Agency for Healthcare Research and Quality,  
21 and the Deputy Assistant Secretary for Minority  
22 Health, conduct a 5-year demonstration project (re-  
23 ferred to in this subsection as the ‘demonstration  
24 project’) for the purpose described in paragraph (2)  
25 under which the Secretary shall—

1           “(A) for the first 18-month period of such  
2           project, award planning grants described in  
3           paragraph (3); and

4           “(B) for the remaining 42-month period of  
5           such project, provide payments to each State  
6           selected under paragraph (4) in accordance  
7           with paragraph (5).

8           “(2) PURPOSE.—The purpose described in this  
9           paragraph is for each State that participates in the  
10          demonstration project to improve access to high-  
11          quality outpatient care for individuals receiving serv-  
12          ices under the State plan (or waiver of such plan)  
13          who are living with sickle cell disease (with a focus  
14          on, but not limited to, young adults and pregnant  
15          women), to improve clinical, mental health, ancillary,  
16          and support services, and to reduce overall and long-  
17          term costs, as appropriate, to the State associated  
18          with treating individuals with sickle cell disease  
19          under the State plan (or waiver of such plan)  
20          through the following activities:

21                 “(A) Supporting the creation or augmenta-  
22                 tion of multi-disciplinary care teams that in-  
23                 clude the physicians needed to adequately treat  
24                 an individual for sickle cell disease and its com-  
25                 plications, as determined by the Secretary in

1 consultation with the appropriate stakeholders,  
2 including organizations representing sickle cell  
3 disease patients, hematologists, and other spe-  
4 cialists in sickle cell disease care and treatment.

5 “(B) Conducting an assessment of the bar-  
6 riers to care experienced by individuals with  
7 sickle cell disease enrolled under the State plan  
8 (or waiver of such plan), taking into account so-  
9 cial, demographic, and economic factors, geog-  
10 raphy, provider shortages, and other issues con-  
11 tributing to health inequities, as determined by  
12 the Secretary in consultation with relevant  
13 stakeholders, including organizations rep-  
14 resenting sickle cell disease patients, hema-  
15 tologists, and other specialists in sickle cell dis-  
16 ease care and treatment.

17 “(C) Identifying best practices for improv-  
18 ing health equity for individuals with sickle cell  
19 disease enrolled under the State plan (or waiver  
20 of such plan) which take into account the re-  
21 sults of the assessment described in subpara-  
22 graph (B), and communicating such best prac-  
23 tices through the provision of education, train-  
24 ing, and technical assistance to providers par-  
25 ticipating under the State plan (or waiver of

1 such plan), including to care teams described in  
2 subparagraph (A).

3 “(D) Expanding expertise of providers par-  
4 ticipating under the State plan (or waiver of  
5 such plan) on care for sickle cell disease by dis-  
6 seminating clinical practice guidelines for sickle  
7 cell disease and providing education, training,  
8 and technical assistance with respect to such  
9 guidelines to such providers.

10 “(E) Ensuring that sickle cell disease pa-  
11 tients enrolled under the State plan (or waiver  
12 of such plan) are getting primary and preven-  
13 tive services in an appropriate outpatient set-  
14 ting or through telehealth services, as appro-  
15 priate, including by providing additional reim-  
16 bursement for care coordinators, community  
17 health workers, and other non-traditional serv-  
18 ice providers.

19 “(F) Developing an individualized, com-  
20 prehensive, patient-centered care plan for indi-  
21 viduals with sickle cell disease that accommo-  
22 dates patient preferences in a culturally and lin-  
23 guistically appropriate manner.

24 “(G) Ensuring that sickle cell disease pa-  
25 tients enrolled under the State plan (or waiver

1 of such plan) are provided with coordination of,  
2 and access to, the following services, as deter-  
3 mined to be clinically appropriate:

4 “(i) Treatments and medications, in-  
5 cluding chronic and exchange transfusions  
6 and disease-modifying medications.

7 “(ii) Appropriate diagnostic testing  
8 such as magnetic resonance imaging.

9 “(iii) Pain management treatment  
10 and palliative care.

11 “(iv) Services provided by subspecial-  
12 ists such as obstetricians and gyne-  
13 cologists, reproductive health specialists,  
14 urologists, ophthalmologists, neurologists,  
15 nephrologists, psychologists, orthopedists,  
16 cardiologists, and pulmonologists.

17 “(v) Supportive clinical services, in-  
18 cluding vision and dental care.

19 “(vi) Mental health services and sub-  
20 stance use disorder treatment.

21 “(vii) Transportation to medical serv-  
22 ices and social support services and refer-  
23 rals to community-based organizations.

24 “(viii) Any other therapies approved  
25 by the Food and Drug Administration for

1 the treatment of sickle cell disease or its  
2 complications.

3 “(ix) Any other services deemed ap-  
4 propriate for the treatment of sickle cell  
5 disease or its complications by the State.

6 “(H) Providing other services or taking  
7 other actions deemed necessary to improve  
8 treatment of sickle cell disease under the State  
9 plan (or waiver of such plan), as determined by  
10 the Secretary in coordination with relevant  
11 stakeholders, including organizations rep-  
12 resenting sickle cell disease patients, hema-  
13 tologists, and other specialists in sickle cell dis-  
14 ease care and treatment.

15 “(3) PLANNING GRANTS.—

16 “(A) IN GENERAL.—The Secretary shall  
17 award planning grants to at least 10 States se-  
18 lected in accordance with subparagraph (B) for  
19 purposes of preparing an application described  
20 in paragraph (4)(C) and carrying out the activi-  
21 ties described in subparagraph (C).

22 “(B) SELECTION.—In selecting States for  
23 purposes of this paragraph, the Secretary  
24 shall—

1           “(i) select States that have a State  
2 plan approved under this title;

3           “(ii) give priority to States that have  
4 participated in the sickle cell disease sur-  
5 veillance data collection program of the  
6 Centers for Disease Control and Preven-  
7 tion or precursors to such program; and

8           “(iii) select States in a manner to rec-  
9 ognize States with a higher prevalence of  
10 sickle cell disease patients that could be  
11 reached through this demonstration  
12 project.

13           “(C) ACTIVITIES DESCRIBED.—Activities  
14 described in this subparagraph are, with respect  
15 to a State, each of the following:

16           “(i) Activities that support an assess-  
17 ment of the treatment needs and gaps in  
18 care in the State for individuals with sickle  
19 cell disease in order to improve the net-  
20 work of providers that treat this popu-  
21 lation, including the following:

22           “(I) An estimate of the number  
23 of individuals enrolled under the State  
24 plan (or a waiver of such plan) who  
25 have sickle cell disease.



1                   “(II) Information on the capacity  
2                   of providers with the knowledge need-  
3                   ed to treat sickle cell disease and the  
4                   complications of sickle cell disease, in-  
5                   cluding information on providers who  
6                   provide such services and their par-  
7                   ticipation under the State plan (or  
8                   waiver of such plan).

9                   “(III) Information on the gaps in  
10                  care for treatment of individuals with  
11                  sickle cell disease under the State  
12                  plan (or waiver of such plan), includ-  
13                  ing information based on the assess-  
14                  ments described in subclauses (I) and  
15                  (II).

16                  “(ii) Activities that, taking into ac-  
17                  count the results of the assessment de-  
18                  scribed in clause (i), support the develop-  
19                  ment of State infrastructure to recruit pro-  
20                  spective providers and provide training and  
21                  technical assistance to providers with re-  
22                  spect to treatment of sickle cell disease  
23                  under the State plan (or a waiver of such  
24                  plan).

1           “(D) FUNDING.—For the purpose of mak-  
2           ing grants under this paragraph, there is appro-  
3           priated to the Secretary, out of any funds in  
4           the Treasury not otherwise appropriated,  
5           \$25,000,000, to remain available until ex-  
6           pended.

7           “(4) POST-PLANNING GRANT STATES.—

8           “(A) IN GENERAL.—The Secretary shall,  
9           with respect to the remaining 42-month period  
10          of the demonstration project conducted under  
11          paragraph (1), select up to 10, but not less  
12          than 5 States in accordance with subparagraph  
13          (B) for purposes of carrying out the activities  
14          described in paragraph (2) and receiving pay-  
15          ments in accordance with paragraph (5). The  
16          Secretary may select all States that received a  
17          planning grant in paragraph (3).

18          “(B) SELECTION.—In selecting States for  
19          purposes of this paragraph, the Secretary  
20          shall—

21                 “(i) select States that received a plan-  
22                 ning grant under paragraph (3) and have  
23                 successfully completed the activities de-  
24                 scribed in subparagraph (C) of such para-  
25                 graph;

1           “(ii) select States that submit to the  
2 Secretary an application in accordance  
3 with the requirements in subparagraph  
4 (C); and

5           “(iii) select States in a manner con-  
6 sistent with reaching as many sickle cell  
7 disease patients as possible through the  
8 demonstration project.

9           “(C) APPLICATIONS.—

10           “(i) IN GENERAL.—A State seeking to  
11 be selected for purposes of this paragraph  
12 shall submit to the Secretary, at such time  
13 and in such form and manner as the Sec-  
14 retary requires, an application that in-  
15 cludes such information as the Secretary  
16 may require, in addition to the following:

17           “(I) A proposed process for car-  
18 rying out the activities described in  
19 paragraph (2).

20           “(II) A review of reimbursement  
21 methodologies and other policies re-  
22 lated to sickle cell disease treatment  
23 under the State plan (or waiver of  
24 such plan) that may create barriers to

1 increasing the number of providers de-  
2 livering such services.

3 “(III) The development of a plan,  
4 taking into account activities carried  
5 out under paragraph (3)(C)(ii), that  
6 will result in long-term and sustain-  
7 able provider networks under the  
8 State plan (or waiver of such plan) for  
9 sickle cell disease.

10 “(IV) A proposed process for re-  
11 porting the information required  
12 under paragraph (6)(A).

13 “(V) The expected financial im-  
14 pact of the demonstration project  
15 under this subsection on the State.

16 “(VI) A description of all funding  
17 sources available to the State to pro-  
18 vide treatment for sickle cell disease  
19 under the State plan (or waiver of  
20 such plan) in the State.

21 “(VII) A preliminary plan for  
22 how the State will sustain any in-  
23 crease in the capacity of providers to  
24 deliver treatment for sickle cell dis-  
25 ease and the complications of sickle

1 cell disease resulting from the dem-  
2 onstration project under this sub-  
3 section after the termination of such  
4 demonstration project.

5 “(VIII) A description of how the  
6 State will coordinate the goals of the  
7 demonstration project with any waiver  
8 granted (or submitted by the State  
9 and pending) pursuant to section  
10 1115 for the delivery of services to  
11 treat sickle cell disease under the  
12 State plan, as applicable.

13 “(ii) CONSULTATION.—In completing  
14 an application under clause (i), a State  
15 shall consult with relevant stakeholders, in-  
16 cluding Medicaid managed care plans, he-  
17 matologists and other sickle cell disease  
18 specialists, and Medicaid beneficiaries and  
19 sickle cell disease advocates, and include in  
20 such application a description of such con-  
21 sultation.

22 “(5) PAYMENTS.—

23 “(A) ENHANCED FMAP FOR SICKLE CELL  
24 DISEASE TREATMENT.—Notwithstanding sec-  
25 tion 1905(b), for each quarter occurring during

1 the period for which the demonstration project  
2 is conducted (after the first 18 months of such  
3 period), the Federal medical assistance percent-  
4 age for each State selected under paragraph (4)  
5 with respect to amounts expended by the State  
6 for medical assistance for medically necessary  
7 services to treat sickle cell disease shall be equal  
8 to 100 percent.

9 “(B) CASE MANAGEMENT SERVICES FOR  
10 SICKLE CELL DISEASE PATIENTS.—

11 “(i) IN GENERAL.—During the period  
12 for which the demonstration project is con-  
13 ducted (after the first 18 months of such  
14 period), a State selected under paragraph  
15 (4) may provide a multi-disciplinary care  
16 team described in paragraph (2)(A) with  
17 payments for the provision of case manage-  
18 ment and care coordination services to an  
19 individual with sickle cell disease who is el-  
20 igible under the State plan (or waiver of  
21 such plan). Payments made to such a team  
22 shall be treated as medical assistance for  
23 purposes of section 1903(a) except that the  
24 Federal medical assistance percentage ap-

1 plicable to such payments shall be equal to  
2 100 percent.

3 “(ii) METHODOLOGY.—A State that  
4 elects to make case management and care  
5 coordination payments to a multi-discipli-  
6 nary care team under this subparagraph  
7 shall specify in a State’s application under  
8 paragraph (4) the methodology the State  
9 will use for determining payment for the  
10 provision of such services. Such method-  
11 ology shall not be limited to a per-member-  
12 per-month basis and may provide (as pro-  
13 posed by the State and subject to approval  
14 by the Secretary) for alternate models of  
15 payment.

16 “(6) REPORTS.—

17 “(A) STATE REPORTS.—A State receiving  
18 payments under paragraph (5) shall, for the pe-  
19 riod of the demonstration project under this  
20 subsection, submit to the Secretary a quarterly  
21 report, with respect to expenditures for treat-  
22 ment of sickle cell disease and complications of  
23 sickle cell disease for which payment is made to  
24 the State under this subsection, on the fol-  
25 lowing:

1           “(i) The specific activities with re-  
2           spect to which payment under this sub-  
3           section was provided.

4           “(ii) The number of individuals en-  
5           rolled under the State plan (or a waiver of  
6           such plan) who received treatment for sick-  
7           le cell disease or complications related to  
8           sickle cell disease under the demonstration  
9           project compared to the estimated number  
10          of such individuals who would have other-  
11          wise received such services in the absence  
12          of such demonstration project.

13          “(iii) The number of individuals en-  
14          rolled under the State plan (or waiver of  
15          such plan) who received treatment for sick-  
16          le cell disease or complications related to  
17          sickle cell disease under the demonstration  
18          project who utilized the services beyond  
19          clinical sickle cell disease services, includ-  
20          ing mental health, ancillary and support  
21          services and the impact on their health  
22          outcomes, including emergency department  
23          visits and inpatient hospital stays.

24          “(iv) The reductions in inpatient days,  
25          reductions in emergency department visits,



1 and reductions in the total cost of care  
2 compared to these metrics before the dem-  
3 onstration project was implemented.

4 “(v) Other matters as determined by  
5 the Secretary.

6 “(B) CMS REPORTS.—

7 “(i) INITIAL REPORT.—Not later than  
8 24 months after the date of enactment of  
9 this subsection, the Administrator of the  
10 Centers for Medicare & Medicaid Services,  
11 in consultation with the Administrator of  
12 the Health Resources and Services Admin-  
13 istration, shall submit to Congress an ini-  
14 tial report on—

15 “(I) the States awarded planning  
16 grants under paragraph (3);

17 “(II) the criteria used in such se-  
18 lection; and

19 “(III) the activities carried out  
20 by such States under such planning  
21 grants.

22 “(ii) INTERIM REPORT.—Not later  
23 than 3 years after the date of enactment  
24 of this subsection, the Administrator of the  
25 Centers for Medicare & Medicaid Services

1 shall, submit to Congress an interim re-  
2 port—

3 “(I) on activities carried out  
4 under the demonstration project  
5 under this subsection;

6 “(II) on the extent to which  
7 States selected under paragraph (4)  
8 have achieved the activities submitted  
9 in their applications under subpara-  
10 graph (C) of such paragraph;

11 “(III) with a description of the  
12 strengths and limitations of such dem-  
13 onstration project; and

14 “(IV) with a plan for the sustain-  
15 ability of such project.

16 “(iii) FINAL REPORT.—Not later than  
17 18 months following the implementation of  
18 the demonstration project, the Secretary  
19 shall submit to Congress and make public  
20 a final report—

21 “(I) providing updates on the  
22 matters reported in the interim report  
23 under clause (ii);

24 “(II) including a description of  
25 any changes made with respect to the

1 demonstration project under this sub-  
2 section after the submission of such  
3 interim report; and

4 “(III) evaluating such dem-  
5 onstration project.

6 “(C) REPORT ON EXPERIENCES OF  
7 STATES.—Not later than 4 years after the date  
8 of the enactment of this subsection, the Admin-  
9 istrator of the Centers for Medicare & Medicaid  
10 Services, in consultation with the Director of  
11 the Agency for Healthcare Research and Qual-  
12 ity, shall submit to Congress a summary on the  
13 experiences of States awarded planning grants  
14 under paragraph (3) and States selected under  
15 paragraph (4).

16 “(7) DATA SHARING AND BEST PRACTICES.—  
17 During the period of the demonstration project  
18 under this subsection, the Secretary shall, in collabo-  
19 ration with States selected under paragraph (4), fa-  
20 cilitate information sharing and the exchange of  
21 identified best practices between—

22 “(A) providers who treat sickle cell disease;  
23 and

24 “(B) States selected under paragraph (4)  
25 and States that were not so selected.

1           “(8) CMS FUNDING.—There is appropriated,  
2           out of any funds in the Treasury not otherwise ap-  
3           propriated, \$50,000,000 to the Centers for Medicare  
4           & Medicaid Services for purposes of implementing  
5           this subsection, including completing the reports to  
6           Congress required under this Act. Such amount  
7           shall remain available until expended.”.

○