118TH CONGRESS
1ST SESSION

S. 904

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

MARCH 21, 2023

Mr. BOOKER 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.

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. MEDICAID DEMONSTRATION PROJECT TO IMPROVE OUTPATIENT CLINICAL CARE FOR INDIVIDUALS WITH SICKLE CELL DISEASE.

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

''(cc) DEMONSTRATION PROJECT TO IMPROVE OUTPATIENT CLINICAL CARE FOR INDIVIDUALS WITH SICKLE CELL DISEASE.—

''(1) IN GENERAL.—Notwithstanding section 1902(a)(1) (relating to statewideness), section 1902(a)(10)(B) (relating to comparability), and any other provision of this title for which the Secretary determines it is necessary to waive in order to implement this subsection, not later than the date that is 1 year after the date of the enactment of this subsection, the Secretary shall, in consultation, as appropriate, with the Administrator of the Health Resources and Services Administration, the Director of the Agency for Healthcare Research and Quality, and the Deputy Assistant Secretary for Minority Health, conduct a 5-year demonstration project (referred to in this subsection as the 'demonstration project') for the purpose described in paragraph (2) under which the Secretary shall—

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

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

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

''(A) Supporting the creation or augmentation of multi-disciplinary care teams that include the physicians needed to adequately treat an individual for sickle cell disease and its complications, as determined by the Secretary in

consultation with the appropriate stakeholders, including organizations representing sickle cell disease patients, hematologists, and other specialists in sickle cell disease care and treatment.

''(B) Conducting an assessment of the barriers to care experienced by individuals with sickle cell disease enrolled under the State plan (or waiver of such plan), taking into account social, demographic, and economic factors, geography, provider shortages, and other issues contributing to health inequities, as determined by the Secretary in consultation with relevant stakeholders, including organizations representing sickle cell disease patients, hematologists, and other specialists in sickle cell disease care and treatment.

''(C) Identifying best practices for improving health equity for individuals with sickle cell disease enrolled under the State plan (or waiver of such plan) which take into account the results of the assessment described in subparagraph (B), and communicating such best practices through the provision of education, training, and technical assistance to providers participating under the State plan (or waiver of

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

''(D) Expanding expertise of providers participating under the State plan (or waiver of such plan) on care for sickle cell disease by disseminating clinical practice guidelines for sickle cell disease and providing education, training, and technical assistance with respect to such guidelines to such providers.

''(E) Ensuring that sickle cell disease patients enrolled under the State plan (or waiver of such plan) are getting primary and preventive services in an appropriate outpatient setting or through telehealth services, as appropriate, including by providing additional reimbursement for care coordinators, community health workers, and other non-traditional service providers.

''(F) Developing an individualized, comprehensive, patient-centered care plan for individuals with sickle cell disease that accommodates patient preferences in a culturally and linguistically appropriate manner.

''(G) Ensuring that sickle cell disease patients enrolled under the State plan (or waiver

of such plan) are provided with coordination of, and access to, the following services, as determined to be clinically appropriate:

"(i) Treatments and medications, including chronic and exchange transfusions and disease-modifying medications.

"(ii) Appropriate diagnostic testing such as magnetic resonance imaging.

"(iii) Pain management treatment and palliative care.

"(iv) Services provided by subspecialists such as obstetricians and gynecologists, reproductive health specialists, urologists, ophthalmologists, neurologists, nephrologists, psychologists, orthopedists, cardiologists, and pulmonologists.

"(v) Supportive clinical services, including vision and dental care.

"(vi) Mental health services and substance use disorder treatment.

"(vii) Transportation to medical services and social support services and referrals to community-based organizations.

"(viii) Any other therapies approved by the Food and Drug Administration for

the treatment of sickle cell disease or its complications.

''(ix) Any other services deemed appropriate for the treatment of sickle cell disease or its complications by the State.

''(H) Providing other services or taking other actions deemed necessary to improve treatment of sickle cell disease under the State plan (or waiver of such plan), as determined by the Secretary in coordination with relevant stakeholders, including organizations representing sickle cell disease patients, hematologists, and other specialists in sickle cell disease care and treatment.

''(3) PLANNING GRANTS.—

''(A) IN GENERAL.—The Secretary shall award planning grants to at least 10 States selected in accordance with subparagraph (B) for purposes of preparing an application described in paragraph (4)(C) and carrying out the activities described in subparagraph (C).

''(B) SELECTION.—In selecting States for purposes of this paragraph, the Secretary shall—

''(i) select States that have a State plan approved under this title;

''(ii) give priority to States that have participated in the sickle cell disease surveillance data collection program of the Centers for Disease Control and Prevention or precursors to such program; and

''(iii) select States in a manner to recognize States with a higher prevalence of sickle cell disease patients that could be reached through this demonstration project.

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

''(i) Activities that support an assessment of the treatment needs and gaps in care in the State for individuals with sickle cell disease in order to improve the network of providers that treat this population, including the following:

''(I) An estimate of the number of individuals enrolled under the State plan (or a waiver of such plan) who have sickle cell disease.

''(II) Information on the capacity of providers with the knowledge needed to treat sickle cell disease and the complications of sickle cell disease, including information on providers who provide such services and their participation under the State plan (or waiver of such plan).

''(III) Information on the gaps in care for treatment of individuals with sickle cell disease under the State plan (or waiver of such plan), including information based on the assessments described in subclauses (I) and (II).

''(ii) Activities that, taking into account the results of the assessment described in clause (i), support the development of State infrastructure to recruit prospective providers and provide training and technical assistance to providers with respect to treatment of sickle cell disease under the State plan (or a waiver of such plan).

"(D) FUNDING.—For the purpose of making grants under this paragraph, there is appropriated to the Secretary, out of any funds in the Treasury not otherwise appropriated, $25,000,000, to remain available until expended.

"(4) POST-PLANNING GRANT STATES.—

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

"(B) SELECTION.—In selecting States for purposes of this paragraph, the Secretary shall—

"(i) select States that received a planning grant under paragraph (3) and have successfully completed the activities described in subparagraph (C) of such paragraph;

''(ii) select States that submit to the Secretary an application in accordance with the requirements in subparagraph (C); and

''(iii) select States in a manner consistent with reaching as many sickle cell disease patients as possible through the demonstration project.

''(C) APPLICATIONS.—

''(i) IN GENERAL.—A State seeking to be selected for purposes of this paragraph shall submit to the Secretary, at such time and in such form and manner as the Secretary requires, an application that includes such information as the Secretary may require, in addition to the following:

''(I) A proposed process for carrying out the activities described in paragraph (2).

''(II) A review of reimbursement methodologies and other policies related to sickle cell disease treatment under the State plan (or waiver of such plan) that may create barriers to

increasing the number of providers delivering such services.

''(III) The development of a plan, taking into account activities carried out under paragraph (3)(C)(ii), that will result in long-term and sustainable provider networks under the State plan (or waiver of such plan) for sickle cell disease.

''(IV) A proposed process for reporting the information required under paragraph (6)(A).

''(V) The expected financial impact of the demonstration project under this subsection on the State.

''(VI) A description of all funding sources available to the State to provide treatment for sickle cell disease under the State plan (or waiver of such plan) in the State.

''(VII) A preliminary plan for how the State will sustain any increase in the capacity of providers to deliver treatment for sickle cell disease and the complications of sickle

cell disease resulting from the demonstration project under this subsection after the termination of such demonstration project.

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

"(ii) CONSULTATION.—In completing an application under clause (i), a State shall consult with relevant stakeholders, including Medicaid managed care plans, hematologists and other sickle cell disease specialists, and Medicaid beneficiaries and sickle cell disease advocates, and include in such application a description of such consultation.

"(5) PAYMENTS.—

"(A) ENHANCED FMAP FOR SICKLE CELL DISEASE TREATMENT.—Notwithstanding section 1905(b), for each quarter occurring during

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

''(B) CASE MANAGEMENT SERVICES FOR SICKLE CELL DISEASE PATIENTS.—

''(i) IN GENERAL.—During the period for which the demonstration project is conducted (after the first 18 months of such period), a State selected under paragraph (4) may provide a multi-disciplinary care team described in paragraph (2)(A) with payments for the provision of case management and care coordination services to an individual with sickle cell disease who is eligible under the State plan (or waiver of such plan). Payments made to such a team shall be treated as medical assistance for purposes of section 1903(a) except that the Federal medical assistance percentage ap-

plicable to such payments shall be equal to 100 percent.

''(ii) METHODOLOGY.—A State that elects to make case management and care coordination payments to a multi-disciplinary care team under this subparagraph shall specify in a State's application under paragraph (4) the methodology the State will use for determining payment for the provision of such services. Such methodology shall not be limited to a per-member-per-month basis and may provide (as proposed by the State and subject to approval by the Secretary) for alternate models of payment.

''(6) REPORTS.—

''(A) STATE REPORTS.—A State receiving payments under paragraph (5) shall, for the period of the demonstration project under this subsection, submit to the Secretary a quarterly report, with respect to expenditures for treatment of sickle cell disease and complications of sickle cell disease for which payment is made to the State under this subsection, on the following:

''(i) The specific activities with respect to which payment under this subsection was provided.

''(ii) The number of individuals enrolled under the State plan (or a waiver of such plan) who received treatment for sickle cell disease or complications related to sickle cell disease under the demonstration project compared to the estimated number of such individuals who would have otherwise received such services in the absence of such demonstration project.

''(iii) The number of individuals enrolled under the State plan (or waiver of such plan) who received treatment for sickle cell disease or complications related to sickle cell disease under the demonstration project who utilized the services beyond clinical sickle cell disease services, including mental health, ancillary and support services and the impact on their health outcomes, including emergency department visits and inpatient hospital stays.

''(iv) The reductions in inpatient days, reductions in emergency department visits,

and reductions in the total cost of care compared to these metrics before the demonstration project was implemented.

''(v) Other matters as determined by the Secretary.

''(B) CMS REPORTS.—

''(i) INITIAL REPORT.—Not later than 18 months after the date of enactment of this subsection, the Administrator of the Centers for Medicare & Medicaid Services, in consultation with the Administrator of the Health Resources and Services Administration, shall submit to Congress an initial report on—

''(I) the States awarded planning grants under paragraph (3);

''(II) the criteria used in such selection; and

''(III) the activities carried out by such States under such planning grants.

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

shall, submit to Congress an interim report—

"(I) on activities carried out under the demonstration project under this subsection;

"(II) on the extent to which States selected under paragraph (4) have achieved the activities submitted in their applications under subparagraph (C) of such paragraph;

"(III) with a description of the strengths and limitations of such demonstration project; and

"(IV) with a plan for the sustainability of such project.

"(iii) FINAL REPORT.—Not later than 1 year following the implementation of the demonstration project, the Secretary shall submit to Congress and make public a final report—

"(I) providing updates on the matters reported in the interim report under clause (ii);

"(II) including a description of any changes made with respect to the

demonstration project under this subsection after the submission of such interim report; and

"(III) evaluating such demonstration project.

"(C) REPORT ON EXPERIENCES OF STATES.—Not later than 3 years after the date of the enactment of this subsection, the Administrator of the Centers for Medicare & Medicaid Services, in consultation with the Director of the Agency for Healthcare Research and Quality, shall submit to Congress a summary on the experiences of States awarded planning grants under paragraph (3) and States selected under paragraph (4).

"(7) DATA SHARING AND BEST PRACTICES.—During the period of the demonstration project under this subsection, the Secretary shall, in collaboration with States selected under paragraph (4), facilitate information sharing and the exchange of identified best practices between—

"(A) providers who treat sickle cell disease; and

"(B) States selected under paragraph (4) and States that were not so selected.

"(8) CMS FUNDING.—There is appropriated, out of any funds in the Treasury not otherwise appropriated, $50,000,000 to the Centers for Medicare & Medicaid Services for purposes of implementing this subsection, including completing the reports to Congress required under this Act. Such amount shall remain available until expended.".

○