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116TH CONGRESS
1ST SESSION

H. R. 1226

To amend title XIX of the Social Security Act to provide States with the option of providing coordinated care for children with complex medical conditions through a health home.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 14, 2019

Ms. CASTOR of Florida (for herself, Mr. BILIRAKIS, Ms. ESHOO, and Ms. HERRERA BEUTLER) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To amend title XIX of the Social Security Act to provide States with the option of providing coordinated care for children with complex medical conditions through a health home.

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 ''Advancing Care for Exceptional Kids Act of 2019'' or the ''ACE Kids Act of 2019''.

SEC. 2. STATE OPTION TO PROVIDE COORDINATED CARE THROUGH A HEALTH HOME FOR CHILDREN WITH MEDICALLY COMPLEX CONDITIONS.

Title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) is amended by inserting after section 1945 the following new section:

"SEC. 1945A. STATE OPTION TO PROVIDE COORDINATED CARE THROUGH A HEALTH HOME FOR CHILDREN WITH MEDICALLY COMPLEX CONDITIONS.

''(a) IN GENERAL.—Notwithstanding section 1902(a)(1) (relating to statewideness) and section 1902(a)(10)(B) (relating to comparability), beginning October 1, 2022, a State, at its option as a State plan amendment, may provide for medical assistance under this title to children with medically complex conditions who choose to enroll in a health home under this section by selecting a designated provider, a team of health care professionals operating with such a provider, or a health team as the child's health home for purposes of providing the child with health home services.

''(b) HEALTH HOME QUALIFICATION STANDARDS.—The Secretary shall establish standards for qualification as a health home for purposes of this section. Such standards shall include requiring designated providers, teams of health care professionals operating with such providers,

and health teams to demonstrate to the State the ability to do the following:

''(1) Coordinate prompt care for children with medically complex conditions, including access to pediatric emergency services at all times.

''(2) Develop an individualized comprehensive pediatric family-centered care plan for children with medically complex conditions that accommodates patient preferences.

''(3) Work in a culturally and linguistically appropriate manner with the family of a child with medically complex conditions to develop and incorporate into such child's care plan, in a manner consistent with the needs of the child and the choices of the child's family, ongoing home care, community-based pediatric primary care, pediatric inpatient care, social support services, and local hospital pediatric emergency care.

''(4) Coordinate access to—

''(A) subspecialized pediatric services and programs for children with medically complex conditions, including the most intensive diagnostic, treatment, and critical care levels as medically necessary; and

''(B) palliative services if the State provides such services under the State plan (or a waiver of such plan).

''(5) Coordinate care for children with medically complex conditions with out-of-State providers furnishing care to such children to the maximum extent practicable for the families of such children and where medically necessary, in accordance with guidance issued under subsection (e)(1) and section 431.52 of title 42, Code of Federal Regulations.

''(6) Collect and report information under subsection (g)(1).

''(c) PAYMENTS.—

''(1) IN GENERAL.—A State shall provide a designated provider, a team of health care professionals operating with such a provider, or a health team with payments for the provision of health home services to each child with medically complex conditions that selects such provider, team of health care professionals, or health team as the child's health home. Payments made to a designated provider, a team of health care professionals operating with such a provider, or a health team for such services shall be treated as medical assistance for purposes of section 1903(a), except that, during the first 2 fiscal year

quarters that the State plan amendment is in effect, the Federal medical assistance percentage applicable to such payments shall be increased by 15 percentage points, but in no case may exceed 90 percent.

''(2) METHODOLOGY.—

''(A) IN GENERAL.—The State shall specify in the State plan amendment the methodology the State will use for determining payment for the provision of health home services. Such methodology for determining payment—

''(i) may be tiered to reflect, with respect to each child with medically complex conditions provided such services by a designated provider, a team of health care professionals operating with such a provider, or a health team, the severity or number of each such child's chronic conditions, life-threatening illnesses, disabilities, or rare diseases, or the specific capabilities of the provider, team of health care professionals, or health team; and

''(ii) shall be established consistent with section 1902(a)(30)(A).

''(B) ALTERNATE MODELS OF PAYMENT.—The methodology for determining payment for

provision of health home services under this section 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.

"(3) PLANNING GRANTS.—

"(A) IN GENERAL.—Beginning October 1, 2022, the Secretary may award planning grants to States for purposes of developing a State plan amendment under this section. A planning grant awarded to a State under this paragraph shall remain available until expended.

"(B) STATE CONTRIBUTION.—A State awarded a planning grant shall contribute an amount equal to the State percentage determined under section 1905(b) (without regard to section 5001 of Public Law 111–5) for each fiscal year for which the grant is awarded.

"(C) LIMITATION.—The total amount of payments made to States under this paragraph shall not exceed $5,000,000.

"(d) COORDINATING CARE.—

"(1) HOSPITAL NOTIFICATION.—A State with a State plan amendment approved under this section shall require each hospital that is a participating

provider under the State plan (or a waiver of such plan) to establish procedures for, in the case of a child with medically complex conditions who is enrolled in a health home pursuant to this section and seeks treatment in the emergency department of such hospital, notifying the health home of such child of such treatment.

''(2) EDUCATION WITH RESPECT TO AVAILABILITY OF HEALTH HOME SERVICES.—In order for a State plan amendment to be approved under this section, a State shall include in the State plan amendment a description of the State's process for educating providers participating in the State plan (or a waiver of such plan) on the availability of health home services for children with medically complex conditions, including the process by which such providers can refer such children to a designated provider, team of health care professionals operating such a provider, or health team for the purpose of establishing a health home through which such children may receive such services.

''(3) FAMILY EDUCATION.—In order for a State plan amendment to be approved under this section, a State shall include in the State plan amendment a description of the State's process for educating

families with children eligible to receive health home services pursuant to this section of the availability of such services. Such process shall include the participation of family-to-family entities or other public or private organizations or entities who provide outreach and information on the availability of health care items and services to families of individuals eligible to receive medical assistance under the State plan (or a waiver of such plan).

''(4) MENTAL HEALTH COORDINATION.—A State with a State plan amendment approved under this section shall consult and coordinate, as appropriate, with the Secretary in addressing issues regarding the prevention and treatment of mental illness and substance use among children with medically complex conditions receiving health home services under this section.

''(e) GUIDANCE ON COORDINATING CARE FROM OUT-OF-STATE PROVIDERS.—

''(1) IN GENERAL.—Not later than October 1, 2020, the Secretary shall issue (and update as the Secretary determines necessary) guidance to State Medicaid directors on—

''(A) best practices for using out-of-State providers to provide care to children with medically complex conditions;

''(B) coordinating care for such children provided by such out-of-State providers (including when provided in emergency and non-emergency situations);

''(C) reducing barriers for such children receiving care from such providers in a timely fashion; and

''(D) processes for screening and enrolling such providers in the respective State plan (or a waiver of such plan), including efforts to streamline such processes or reduce the burden of such processes on such providers.

''(2) STAKEHOLDER INPUT.—In carrying out paragraph (1), the Secretary shall issue a request for information to seek input from children with medically complex conditions and their families, States, providers (including children's hospitals, hospitals, pediatricians, and other providers), managed care plans, children's health groups, family and beneficiary advocates, and other stakeholders with respect to coordinating the care for such children provided by out-of-State providers.

''(f) MONITORING.—A State shall include in the State plan amendment—

''(1) a methodology for tracking reductions in inpatient days and reductions in the total cost of care resulting from improved care coordination and management under this section;

''(2) a proposal for use of health information technology in providing health home services under this section and improving service delivery and coordination across the care continuum (including the use of wireless patient technology to improve coordination and management of care and patient adherence to recommendations made by their provider); and

''(3) a methodology for tracking prompt and timely access to medically necessary care for children with medically complex conditions from out-of-State providers.

''(g) DATA COLLECTION.—

''(1) PROVIDER REPORTING REQUIREMENTS.—In order to receive payments from a State under subsection (c), a designated provider, a team of health care professionals operating with such a provider, or a health team shall report to the State, at

such time and in such form and manner as may be required by the State, the following information:

"(A) With respect to each such provider, team of health care professionals, or health team, the name, National Provider Identification number, address, and specific health care services offered to be provided to children with medically complex conditions who have selected such provider, team of health care professionals, or health team as the health home of such children.

"(B) Information on all applicable measures for determining the quality of health home services provided by such provider, team of health care professionals, or health team, including, to the extent applicable, child health quality measures and measures for centers of excellence for children with complex needs developed under this title, title XXI, and section 1139A.

"(C) Such other information as the Secretary shall specify in guidance.

When appropriate and feasible, such provider, team of health care professionals, or health team, as the

case may be, shall use health information technology in providing the State with such information.

''(2) STATE REPORTING REQUIREMENTS.—

''(A) COMPREHENSIVE REPORT.—A State with a State plan amendment approved under this section shall report to the Secretary (and, upon request, to the Medicaid and CHIP Payment and Access Commission), at such time and in such form and manner determined by the Secretary to be reasonable and minimally burdensome, the following information:

''(i) Information reported under paragraph (1).

''(ii) The number of children with medically complex conditions who have selected a health home pursuant to this section.

''(iii) The nature, number, and prevalence of chronic conditions, life-threatening illnesses, disabilities, or rare diseases that such children have.

''(iv) The type of delivery systems and payment models used to provide services to such children under this section.

''(v) The number and characteristics of designated providers, teams of health care professionals operating with such providers, and health teams selected as health homes pursuant to this section, including the number and characteristics of out-of-State providers, teams of health care professionals operating with such providers, and health teams who have provided health care items and services to such children.

''(vi) The extent to which such children receive health care items and services under the State plan.

''(vii) Quality measures developed specifically with respect to health care items and services provided to children with medically complex conditions.

''(B) REPORT ON BEST PRACTICES.—Not later than 90 days after a State has a State plan amendment approved under this section, such State shall submit to the Secretary, and make publicly available on the appropriate State website, a report on how the State is implementing guidance issued under subsection

(e)(1), including through any best practices adopted by the State.

''(h) RULE OF CONSTRUCTION.—Nothing in this section may be construed—

''(1) to require a child with medically complex conditions to enroll in a health home under this section;

''(2) to limit the choice of a child with medically complex conditions in selecting a designated provider, team of health care professionals operating with such a provider, or health team that meets the health home qualification standards established under subsection (b) as the child's health home; or

''(3) to reduce or otherwise modify—

''(A) the entitlement of children with medically complex conditions to early and periodic screening, diagnostic, and treatment services (as defined in section 1905(r)); or

''(B) the informing, providing, arranging, and reporting requirements of a State under section 1902(a)(43).

''(i) DEFINITIONS.—In this section:

''(1) CHILD WITH MEDICALLY COMPLEX CONDITIONS.—

"(A) IN GENERAL.—Subject to subparagraph (B), the term 'child with medically complex conditions' means an individual under 21 years of age who—

"(i) is eligible for medical assistance under the State plan (or under a waiver of such plan); and

"(ii) has at least—

"(I) one or more chronic conditions that cumulatively affect three or more organ systems and severely reduces cognitive or physical functioning (such as the ability to eat, drink, or breathe independently) and that also requires the use of medication, durable medical equipment, therapy, surgery, or other treatments; or

"(II) one life-limiting illness or rare pediatric disease (as defined in section 529(a)(3) of the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 360ff(a)(3))).

"(B) RULE OF CONSTRUCTION.—Nothing in this paragraph shall prevent the Secretary from establishing higher levels as to the number

or severity of chronic, life threatening illnesses, disabilities, rare diseases or mental health conditions for purposes of determining eligibility for receipt of health home services under this section.

''(2) CHRONIC CONDITION.—The term 'chronic condition' means a serious, long-term physical, mental, or developmental disability or disease, including the following:

''(A) Cerebral palsy.

''(B) Cystic fibrosis.

''(C) HIV/AIDS.

''(D) Blood diseases, such as anemia or sickle cell disease.

''(E) Muscular dystrophy.

''(F) Spina bifida.

''(G) Epilepsy.

''(H) Severe autism spectrum disorder.

''(I) Serious emotional disturbance or serious mental health illness.

''(3) HEALTH HOME.—The term 'health home' means a designated provider (including a provider that operates in coordination with a team of health care professionals) or a health team selected by a

child with medically complex conditions (or the family of such child) to provide health home services.

''(4) HEALTH HOME SERVICES.—

''(A) IN GENERAL.—The term 'health home services' means comprehensive and timely high-quality services described in subparagraph (B) that are provided by a designated provider, a team of health care professionals operating with such a provider, or a health team.

''(B) SERVICES DESCRIBED.—The services described in this subparagraph shall include—

''(i) comprehensive care management;

''(ii) care coordination, health promotion, and providing access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-State providers, as medically necessary;

''(iii) comprehensive transitional care, including appropriate follow-up, from inpatient to other settings;

''(iv) patient and family support (including authorized representatives);

''(v) referrals to community and social support services, if relevant; and

''(vi) use of health information technology to link services, as feasible and appropriate.

''(5) DESIGNATED PROVIDER.—The term 'designated provider' means a physician (including a pediatrician or a pediatric specialty or subspecialty provider), children's hospital, clinical practice or clinical group practice, prepaid inpatient health plan or prepaid ambulatory health plan (as defined by the Secretary), rural clinic, community health center, community mental health center, home health agency, or any other entity or provider that is determined by the State and approved by the Secretary to be qualified to be a health home for children with medically complex conditions on the basis of documentation evidencing that the entity has the systems, expertise, and infrastructure in place to provide health home services. Such term may include providers who are employed by, or affiliated with, a children's hospital.

''(6) TEAM OF HEALTH CARE PROFESSIONALS.—The term 'team of health care professionals' means a team of health care professionals (as described in the State plan amendment under this section) that may—

"(A) include—

"(i) physicians and other professionals, such as pediatricians or pediatric specialty or subspecialty providers, nurse care coordinators, dietitians, nutritionists, social workers, behavioral health professionals, physical therapists, occupational therapists, speech pathologists, nurses, individuals with experience in medical supportive technologies, or any professionals determined to be appropriate by the State and approved by the Secretary;

"(ii) an entity or individual who is designated to coordinate such a team; and

"(iii) community health workers, translators, and other individuals with culturally appropriate expertise; and

"(B) be freestanding, virtual, or based at a children's hospital, hospital, community health center, community mental health center, rural clinic, clinical practice or clinical group practice, academic health center, or any entity determined to be appropriate by the State and approved by the Secretary.

"(7) HEALTH TEAM.—The term 'health team' has the meaning given such term for purposes of section 3502 of Public Law 111–148.".

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