[DISCUSSION DRAFT]

114th Congress
2d Session

H. R. ______

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, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Mr. Barton (for himself and Ms. Castor of Florida) introduced the following bill; which was referred to the Committee on

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, and for other purposes.

1 Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

2 SECTION 1. SHORT TITLE.

3 This Act may be cited as the “Advancing Care for Exceptional Kids Act” or the “ACE Kids Act”.


SEC. 2. ESTABLISHMENT OF STATE MEDICAID OPTION TO PROVIDE COORDINATED CARE THROUGH A HEALTH HOME FOR CHILDREN WITH COMPLEX MEDICAL CONDITIONS.

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

"STATE OPTION TO PROVIDE COORDINATED CARE THROUGH A HEALTH HOME FOR CHILDREN WITH COMPLEX MEDICAL CONDITIONS

"Sec. 1947. (a) 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 which the Secretary determines it is necessary to waive in order to implement this section, beginning January 1, 2018, a State, at its option as a State plan amendment, may provide for medical assistance under this title to children with medically complex conditions for whom a designated provider, or a team of health care professionals, is selected as the individual’s health home for purposes of providing the individual with health home services.

“(b) Payments.—

“(1) In General.—Under this section, a State shall provide a designated provider, or a team of health care professionals, with payments for the pro-
vision of health home services to each child with medically complex conditions for whom there is selected such provider or such team as the individual’s health home. Such payments for such services shall be treated as medical assistance for purposes of section 1903(a), except that, during the first 8 fiscal year quarters that the State plan amendment is in effect, the Federal medical assistance percentage applicable to such payments shall be equal to 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 under paragraph (1). Such methodology for determining payment—

“(i) may be tiered to reflect, with respect to each child with medically complex conditions and each designated provider, or team of health care professionals, the severity or number of such child’s chronic conditions, life-threatening illnesses, or rare diseases or the specific capabilities of such provider or such team; and
“(ii) shall be established consistent with section 1902(a)(30)(A).

“(B) MODELS OF PAYMENT.—The methodology under subparagraph (A) may include (but is not required to include) payments made on a per-member per-month basis and may include shared savings models, pay-for-performance models, contingency awards dependent on reducing utilization of emergency departments, or other incentive-based approaches.

“(c) COORDINATING CARE.—

“(1) HOSPITAL REFERRALS.—A State may include in the State plan amendment under this section a requirement for hospitals participating under the State plan or a waiver of such plan to establish procedures for hospital emergency departments to refer children with medically complex conditions to designated providers.

“(2) EDUCATION WITH RESPECT TO AVAILABILITY OF HEALTH HOME SERVICES.—A State shall include in the State plan amendment under this section a description of the State’s process for educating providers participating in the State plan or a waiver of such plan about the availability of health home services for children with medically
complex conditions, including the process by which such providers can refer such children to designated providers to receive such services.

“(3) COORDINATING CARE FROM OUT-OF-STATE PROVIDERS.—

“(A) IN GENERAL.—A State electing to provide medical assistance pursuant to subsection (a) shall provide guidance, consistent with guidance from the Administrator of the Centers for Medicare & Medicaid Services, to designated providers receiving payment under this section, regarding the State’s policies and procedures for accessing care for children with medically complex conditions from out-of-State providers. For the purpose of helping facilitate medically necessary care for such children, such guidance shall include information on how out-of-State providers who provide services to such children can receive payment by such State Medicaid program.

“(B) BEST PRACTICES.—A State electing to provide medical assistance pursuant to subsection (a) shall consider adopting best practices for providing access to out-of-State providers for children with medically complex con-
ditions consistent with guidance provided by the Administrator of the Centers for Medicare & Medicaid Services.

“(d) DATA COLLECTION.—

“(1) PROVIDER REPORTING REQUIREMENTS.—

As a condition of receiving payment under this section, a designated provider receiving payment for health home services under this section shall report to the State, in accordance with such guidance as the Administrator of the Centers for Medicare & Medicaid Services shall specify, on all applicable measures for determining the quality of such services.

“(2) STATE REPORTING REQUIREMENTS.—A State electing to provide medical assistance pursuant to subsection (a) shall collect and provide to the Secretary (and to the Medicaid and CHIP Payment and Access Commission upon request), in a form and manner determined by the Secretary, the following information:

“(A) Information reported under paragraph (1).

“(B) The number of children with medically complex conditions who have selected a health home.
“(C) The nature, number, and prevalence of chronic conditions, life-threatening illnesses, or rare diseases that such children have.

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

“(E) The number and characteristics of providers serving as health homes under this section.

“(F) The extent to which such children receive services under a State plan or a waiver of such plan from out-of-State providers, and the extent to which such services were provided on an emergency or non-emergency basis.

“(e) 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) 2 chronic conditions;

“(II) 1 chronic condition that affects two or more body systems and reduces cognitive or physical functioning (such as the ability to eat, drink, or breathe independently); or

“(III) 1 life-threatening illness or rare disease, such as a form of cancer or a rare disease (as defined in section 481(c) of the Public Health Service Act).

“(B) RULE OF CONSTRUCTION.—Nothing in this paragraph shall prevent a State participating under this section from establishing higher levels as to the number or severity of chronic conditions, life-threatening illnesses, or rare diseases for purposes of determining eligibility for receipt of health home services under this section.

“(2) CHRONIC CONDITION.—The term ‘chronic condition’ shall include, at a minimum, each of the following:

“(A) Cerebral palsy.

“(B) Cystic fibrosis.

“(C) HIV/AIDS.
“(D) A congenital heart condition that impedes proper function of the heart.

“(E) Blood problems such as anemia or sickle cell disease.

“(F) Muscular dystrophy.

“(G) Spina bifida.

“(H) Epilepsy.

“(I) Severe autism spectrum disorder.

“(J) Serious emotional disturbance or serious mental health condition.

“(3) Health Home.—The term ‘health home’ means a designated provider or a team of health care professionals (who may employed by or affiliated with a children’s hospital) selected to provide health home services to a child with medically complex conditions.

“(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, or a team of health care professionals.

“(B) Services Described.—The services described in this subparagraph shall, at a minimum, include—
“(i) comprehensive care management;
“(ii) care coordination and health promotion;
“(iii) comprehensive transitional care, including appropriate follow-up, from inpatient to other settings;
“(iv) patient and family support (including authorized representatives);
“(v) referral to community and social support services, if relevant;
“(vi) use of health information technology to link services, as feasible and appropriate; and
“(vii) coordinating access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-State providers, as medically necessary.

“(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, 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 Administrator of the Centers for Medicare & Medicaid Services] to be qualified to be a health home for children with medically complex conditions on the basis of documentation evidencing that the physician, practice, or clinic has the systems and infrastructure in place to provide health home services.

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

“(A) include physicians and other professionals, such as a pediatrician or pediatric specialty or subspecialty provider, nurse care coordinator, nutritionist, social worker, behavioral health professional, or any professionals deemed appropriate by the State [and approved by the Administrator of the Centers for Medicare & Medicaid Services]; and

“(B) be free standing, 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
deemed appropriate by the State [and approved by the Administrator of the Centers for Medicare & Medicaid Services].”

SEC. 3. RULE OF CONSTRUCTION ON FREEDOM OF CHOICE.

Nothing in section 1947 of the Social Security Act (as added by this Act) may be construed, with respect to children with medically complex conditions (as defined in such section 1947), to limit the choice of providers by such children under section 1902(a)(23) of the Social Security Act (42 U.S.C. 1396a(a)(23)).

SEC. 4. GUIDANCE ON COORDINATING CARE FROM OUT-OF-STATE PROVIDERS.

(a) IN GENERAL.—Not later than one year after the date of the enactment of this section, the Administrator of the Centers for Medicare & Medicaid Services shall issue guidance to State Medicaid Directors on best practices for using out-of-State providers to provide care to children with medically complex conditions (as defined in section 1947 of the Social Security Act, as added by this Act), including guidance regarding—

(1) arranging access to, and providing payment for, care for such children provided by such providers;

(2) reducing barriers for such children receiving care from such providers in a timely fashion;
(3) screening and enrolling such providers, including efforts to streamline the process or reduce the burden on providers; and

(4) providing for payment to such providers who provide care for children with medically complex conditions in emergency and non-emergency situations.

(b) Stakeholder Input.—In carrying out subsection (a), the Administrator of the Centers for Medicare & Medicaid Services shall issue a Request For Information to seek input from States, providers (including children’s hospitals, hospitals, pediatricians and other providers), managed care plans, children’s health groups, beneficiary advocates, and other stakeholders.

SEC. 5. MACPAC REPORT.

(a) In General.—Not later than 18 months after the date of the enactment of this Act, the Medicaid and CHIP Payment and Access Commission established under section 1900 of the Social Security Act (42 U.S.C. 1396) shall submit a report to Congress and the Secretary of Health and Human Services on children with medically complex conditions which describes options for defining the characteristics of such children and which includes the information described in subsection (b) and such recommendations as the Commission deems appropriate.
(b) INFORMATION TO BE INCLUDED.—The information described in this subsection is the following information:

(1) The characteristics of children with medically complex conditions, including—

(A) a literature review examining—

(i) research on such children; and

(ii) clinical measures or other groupings which enable comparison among such children; and

(B) information gathered from consultation with medical and academic experts engaged in research about or treatment of such children.

(2) Children with medically complex conditions who are enrolled in a State Medicaid plan under title XIX of the Social Security Act (or a waiver of such plan), including—

(A) the number of such children;

(B) the chronic conditions, life-threatening illnesses, or rare diseases that such children have;

(C) the number of such children receiving services under each delivery system or payment model, including health homes, fee-for-service,
primary care case managers, or managed care plans; and

(D) the extent to which such children receive care coordination services.

(3) The providers who serve children with medically complex conditions, such as physicians (including pediatricians and pediatric specialty or sub-specialty providers), children’s hospitals, clinical practices or clinical group practices, rural clinics, community health centers, community mental health centers, or home health agencies.

(4) The extent to which children with medically complex conditions receive services from out-of-State providers that receive payment under the State Medicaid plan under title XIX of the Social Security Act (or a waiver of such plan) and any barriers to receiving such services in a timely fashion, including any variation in access to such services by delivery system.