H. R. 3325

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

JULY 20, 2017

Mr. Barton (for himself, Ms. Castor of Florida, Mr. Gene Green of Texas, Ms. Eshoo, Mr. Reichert, and Ms. Herrera Beutler) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 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 “Advancing Care for
5  Exceptional Kids Act” or the “ACE Kids Act”.

Be it enacted by the Senate and House of Representa-
tives of the United States of America in Congress assembled,
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), section 1902(a)(23) (relating to freedom of choice), section 1902(a)(30)(A) (relating to equal access), and any other provision of this title which the Secretary determines it is necessary to waive in order to implement this section (other than section 1905(a)(4)(B) (relating to early and periodic screening, diagnostic, and treatment services)), beginning on 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 who select (or for whom is selected) a designated provider, or a team of health care professionals, as the individual’s health home for purposes of providing such children with health home services.
“(b) PAYMENTS.—

“(1) IN GENERAL.—A State shall provide, with respect to health home services furnished to each child with medically complex conditions who selects or for whom there is selected a designated provider or a team as the child’s health home pursuant to this section, to such designated provider or team with payments for the provision of such health home services. The State shall make such payments regardless of whether a child with medically complex conditions described in the preceding sentence receives health home services under this section through a fee-for-service or managed care system. Such payments for such services shall be treated as medical assistance (as defined in section 1905(a)) for purposes of payments made under 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 increased by 20 percentage points, but in no case shall 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 pay-
ment 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, disabilities, or rare diseases or the specific capabilities of such provider or such team;

“(ii) shall be established consistent with section 1902(a)(30)(A); and

“(iii) shall take into account any feedback the State receives from stakeholders.

“(B) MODELS OF PAYMENT.—The methodology under subparagraph (A) may 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, as defined by the State.

“(C) ENSURING HIGH-QUALITY CARE.— The methodology under subparagraph (A) shall include the State’s strategy for evaluating the
quality of care provided within a health home pursuant to this section. Such strategy shall take into account the following quality measures that may be applicable for health homes that serve children with medically complex conditions:

“(i) Child health quality measures and measures for centers of excellence for children with complex needs developed under this title, title XXI, and section 1139A.

“(ii) The Healthcare Effectiveness Data and Information Set (HEDIS).

“(iii) The health home’s expertise in providing, integrating, or coordinating prompt care for children with complex medical conditions, including access to pediatric emergency services at all times.

“(iv) The health home’s ability to coordinate and integrate the full range of pediatric medical, surgical, and behavioral specialists and subspecialists needed, based on clinical qualifications (such as board certification) and patient preference on the care team to care for children with complex medical conditions, as well as pro-
providers offering specialized services, such as
rehabilitative and habilitative health care
and private-duty nursing, if needed.

“(v) The health home’s ability to co-
ordinate the provision of outpatient care
needs, including durable medical equip-
ment, medical supplies, and medical foods,
if needed.

“(vi) The health home’s ability to ar-
range and coordinate care for children with
complex medical conditions from out-of-
State providers to the maximum extent
practicable for the families of such children
and where medically necessary in accord-
ance with the guidance from the Adminis-
trator of the Centers for Medicare & Med-
icaid Services issued pursuant to section 4
of the ACE Kids Act.

“(vii) The health home’s ability to co-
ordinate and collect payments from liable
third parties (including parties described in
section 1902(a)(25)(A)) for care and serv-
ces provided or arranged for by the entity.
“(viii) The health home’s ability to collect and report on the information required under subsection (d)(1).

“(c) COORDINATING CARE.—

“(1) HOSPITAL REFERRALS.—A State shall include in the State plan amendment under this section—

“(A) a requirement for hospitals participating under the State plan under this title or a waiver of such plan to establish procedures for hospital emergency departments to refer children with medically complex conditions enrolled in a health home pursuant to this section to designated providers or teams of health care professionals who are participating in such health home; and

“(B) a requirement for the State to notify such hospitals of any designated providers or teams of health care professionals who are participating in a health home.

“(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.
under this title 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 (or a team of health care professionals) to receive such services.

“(3) FAMILY EDUCATION.—A State shall include in the State plan amendment under this section 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 may include the participation of family-to-family entities or other public or private organizations or entities who provide outreach and information about the availability of health care items and services to families of individuals eligible to receive medical assistance under the State plan under this title (or a waiver of the plan).

“(4) 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 issued pursuant to section 4 of the ACE Kids Act, to designated providers, or teams of health care professionals, 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. The guidance provided by the State under the preceding sentence shall include information on how out-of-State providers who provide services to children with medically complex conditions enrolled in a health home in such State pursuant to this section may receive payment under the State plan under this title (or a waiver of the plan).

“(B) Best practices.—A State electing to provide medical assistance pursuant to subsection (a) shall, to the extent practicable, adopt best practices for providing access to out-of-State providers for children with medically complex conditions consistent with guidance issued by the Administrator of the Centers for Medicare & Medicaid Services pursuant to section 4 of the ACE Kids Act. The Administrator of the Centers for Medicare & Medicaid Serv-
ices shall make available on a public Internet
website of the Centers for Medicare & Medicaid
Services a list of the States with a State plan
amendment approved under this section and the
degree to which (as determined by the Adminis-
trator) such States have adopted the best prac-
tices recommended by the Administrator in
such guidance.

“(C) MENTAL HEALTH COORDINATION.—A
State shall consult and coordinate, as appro-
priate, with the Assistant Secretary for Mental
Health and Substance Use, in addressing issues
regarding the prevention and treatment of men-
tal illness and substance use among children
with medically complex conditions receiving
home health services pursuant to this section.

“(D) FAILURE TO IMPLEMENT BEST PRAC-
tICES.—Beginning 180 days after the date on
which guidance is issued by the Administrator
of the Centers for Medicare & Medicaid Serv-
ices pursuant to section 4 of the ACE Kids Act,
in the case of a State with a State plan amend-
ment approved under this section that the Ad-
ministrator of the Centers for Medicare & Med-
icaid Services determines has not adopted the
best practices recommended by the Administrator in such guidance, the increase of the Federal medical assistance percentage applied under subsection (b)(1) shall be reduced by 10 percentage points.

“(d) DATA COLLECTION.—

“(1) PROVIDER REPORTING REQUIREMENTS.—

As a condition of receiving payment under this section, a designated provider or team of health care professionals receiving payment for health home services under this section shall report to the State the following information:

“(A) With respect to each such provider or team, the name, National Provider Identification number, address, and specific health care services offered to be provided to children with medically complex conditions enrolled in the health home involved.

“(B) Information on all applicable measures used by such provider or team for purposes of assisting in assessing the quality and effectiveness of such services.

“(C) Other such information as the Administrator of the Centers for Medicare & Medicaid Services shall specify in guidance.
“(2) STATE REPORTING REQUIREMENTS.—A State electing to provide medical assistance pursuant to subsection (a) shall collect and provide to the Administrator of the Centers for Medicare & Medicaid Services (and to the Medicaid and CHIP Payment and Access Commission upon request), in a form and manner determined by the Administrator to be reasonable and minimally burdensome, the following information:

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

“(B) The number of children with medically complex conditions who have selected a health home or for whom a health home was selected pursuant to this section.

“(C) The nature, number, and prevalence of chronic conditions, life-threatening illnesses, disabilities, 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 or health care professionals designated as health homes pursuant to this sec-
tion, including the number and characteristics of out-of-State providers or health care professionals who provide health care items and services to such children.

“(F) The extent to which such children receive health care items and services under a State plan under this title 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.

“(G) Quality measures developed specifically with respect to health care items and services furnished to children with medically complex conditions.

“(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 under this title or under a waiver of such plan; and

“(ii) has at least—
“(I) A chronic condition that affects three or more organ systems and severely reduces cognitive or physical functioning (such as the ability to eat, drink, or breathe independently) and which also requires the use of medication, durable medical equipment, therapy, surgery, or other treatment or treatments; or

“(II) A 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. 360fff(a)(3))), such as a form of cancer.

“(B) Rule of construction.—Nothing in this paragraph shall prevent a State with a State plan amendment approved under this section, with respect to determining the eligibility of a children with medically complex conditions to receive health home services under such State plan amendment, from increasing the number or severity of chronic conditions, life-threatening illnesses, disabilities, or rare diseases.
“(2) CHRONIC CONDITION.—The term ‘chronic condition’ means a serious, long-term physical, mental, or developmental disability or disease, such as any of 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 or a team of health care professionals 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 the services described in subparagraph (B) that are provided by a designated provider, or a team of health care pro-
professionals in a timely manner and on a high-quality basis.

“(B) SERVICES DESCRIBED.—The services described in this subparagraph shall, at a minimum, include—

“(i) an individualized comprehensive pediatric family-centered care plan for each child with complex medical conditions assigned to the health home that provides seamless pediatric care coordination by a customized care team with a designated team lead for each such child and the child’s family;

“(ii) care coordination, health promotion, and providing access to the full range of pediatric specialty and subspecialty medical services, including early and periodic screening, diagnostic, and treatment services described in section 1905(a)(4)(B) and services from out-of-State providers, as medically necessary;

“(iii) comprehensive transitional care, including appropriate follow-up, from inpatient to other settings;
“(iv) working with the family of each child with complex medical conditions assigned to the health home to develop and incorporate ongoing home care, community based pediatric primary care, care from the most medically appropriate or family-preferred children’s hospital, social support services, and local hospital pediatric emergency care into the child’s care plan, to the extent consistent with family choice and the needs of the child;

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

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

“(vii) in the case of a State that, as of the date of the enactment of the ACE Kids Act, provides under the State plan under this title (or a waiver of such plan) for palliative services, palliative services;

“(viii) efforts to include, with respect to the delivery of care and the development, operation, and evaluation of the
health home’s services, the families of children with complex medical conditions;

“(ix) ensuring that any interactions with each child with complex medical conditions and the child’s family occurs in a culturally and linguistically appropriate manner; and

“(x) providing integration with, and access to, subspecialized pediatric services and programs for children with complex medical conditions, including the most intensive diagnostic, treatment, and critical care levels as medically necessary and appropriate out-of-State care.

“(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 of Health and Human Services), 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 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 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.—

“(A) In General.—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—

“(i) include 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 Administrator
of the Centers for Medicare & Medicaid Services; and

“(ii) 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 determined to be appropriate by the State and approved by the Administrator of the Centers for Medicare & Medicaid Services.

“(B) INCLUSION.—Such term includes—

“(i) an entity or individual who is designated to coordinate such team; and

“(ii) community health workers, translators, and other individuals with culturally-appropriate expertise.”.

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

Nothing in section 1947 of the Social Security Act (as added by section 2 of this Act) may be construed, with respect to children with medically complex conditions (as defined in such section 1947), to limit the choice of such children or their families to participate (or not participate in) a health home (as defined in such section 1947).
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 Act, 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 section 2 of this Act), including guidance regarding—

(1) arranging access to, and providing payment for, care for such children furnished by such out-of-State providers (including when provided in emergency and non-emergency situations);

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

(3) processes for screening and enrolling such providers in the State plan under title XIX of the Social Security Act (or a waiver of the plan), including efforts to streamline such processes or reduce the burden of such processes on providers.

(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 children with medically complex conditions (as defined in section 1947 of the Social Security Act, as added by section 2 of this Act), including guidance regarding—
Act, as added by section 2 of this Act) 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 furnished by out-of-State providers.

(c) STATE PARTICIPATION.—Not later than 90 days after the issuance of the best practice guidelines under subsection (a), States with a State plan amendment in effect under section 1947 of the Social Security Act shall submit to the Secretary of Health and Human Services, and make publicly available on the appropriate Internet website of the State, information on how the State is achieving the purposes described in such subsection, including any of such best practices adopted by the State.

SEC. 5. MACPAC REPORT.

(a) IN GENERAL.—Not later than 24 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 to Congress and the Secretary of Health and Human Services a report on children with medically complex conditions that—

(1) describes options for defining the characteristics of such children;
(2) includes the information described in subsection (b); and

(3) includes such recommendations as the Commission determines is appropriate.

(b) INFORMATION TO BE INCLUDED.—The information described in this subsection is, to the extent practical and available, the following information:

(1) With respect to the characteristics of children with medically complex conditions (as defined in section 1947 of the Social Security Act (as added by section 2 of this Act))—

(A) a literature review examining—

(i) research on such children;

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

(iii) demographic characteristics, including primary language, based on available data; and

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

(2) Information relating to children with medically complex conditions who are receiving medical
assistance under 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, disabilities, injuries, 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 (as defined in such section 1947), fee-for-service systems, primary care case managers, or managed care plans; and

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

(3) Information on the providers who furnish health care items and services to children with medically complex conditions, such as physicians (including pediatricians and pediatric specialty or subspecialty 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 (or are denied) health
care items and 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 from such providers in a timely fashion, including any variation in access to such services furnished by such providers, disaggregated by delivery system.

(5) The amount and nature of the total resources used to provide care to individual children with medically complex conditions during the period in which such a child is enrolled in a health home, including—

(A) the amount of capital spent in providing such care;

(B) the resources used to provide such care during any waiting period with respect to the enrollment of the child in the State plan under title XIX of the Social Security Act (or a waiver of such plan) or any necessary approval under the State plan for the furnishing of such services (such as inpatient costs awaiting discharge);

(C) the cost of the coordination of such child’s care;
(D) the cost of providing to such child any non-medical benefits (such as transportation and home services); and

(E) the clinical costs of providing such care.