115TH CONGRESS
1ST SESSION
S. 428

To amend titles XIX and XXI of the Social Security Act to authorize States to provide coordinated care to children with complex medical conditions through enhanced pediatric health homes, and for other purposes.

IN THE SENATE OF THE UNITED STATES
FEBRUARY 16, 2017
Mr. GRASSLEY (for himself, Mr. BENNET, Mr. PORTMAN, Ms. HARRIS, Mr. BLUNT, Mr. NELSON, Mr. BROWN, Mr. GARDNER, and Mrs. MURRAY) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL
To amend titles XIX and XXI of the Social Security Act to authorize States to provide coordinated care to children with complex medical conditions through enhanced pediatric health homes, 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 of 2017” or the “ACE Kids Act of
6 2017”.

Be it enacted by the Senate and House of Representa-
tives of the United States of America in Congress assembled,
SEC. 2. STATE OPTION TO PROVIDE COORDINATED CARE TO CHILDREN WITH COMPLEX MEDICAL CONDITIONS THROUGH ENHANCED PEDIATRIC HEALTH HOMES.

(a) State Medicaid Plan Amendment.—Title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) is amended by inserting after section 1946 the following new section:

"STATE OPTION TO PROVIDE COORDINATED CARE THROUGH ENHANCED PEDIATRIC HEALTH HOMES FOR CHILDREN WITH COMPLEX MEDICAL CONDITIONS"

"SEC. 1947. (a) IN GENERAL.—Notwithstanding section 1902(a)(1) (relating to statewideness) and section 1902(a)(10)(B) (relating to comparability), beginning January 1, 2018, a State, at its option as a State plan amendment, may establish an EPHH program to provide medical assistance under this title for EPHH services furnished to children with complex medical conditions who are enrolled in an enhanced pediatric health home (also referred to in this section as an EPHH) under an EPHH program agreement.

"(b) DEFINITIONS.—In this section:

"(1) CHILD WITH COMPLEX MEDICAL CONDITIONS.—The term ‘child with complex medical conditions’ means an individual who—"
“(A) is enrolled in a State plan under this title or title XXI or under a waiver of such plan;

“(B) is under 21 years of age; and

“(C) has a chronic medical condition or serious injury that—

“(i) affects two or more body systems;

“(ii) affects cognitive or physical functioning (such as reducing the ability to perform the activities of daily living, including the ability to engage in movement or mobility, eat, drink, communicate, or breathe independently); and

“(iii) either—

“(I) requires intensive healthcare interventions (such as multiple medications, therapies, or durable medical equipment) and intensive care coordination to optimize health and avoid hospitalizations or emergency department visits; or

“(II) meets the criteria for medical complexity under existing risk adjustment methodologies using a recognized, publicly available pediatric
grouping system (such as the pediatric complex conditions classification system or the Pediatric Medical Complexity Algorithm) selected by the Secretary in close collaboration with the State agencies responsible for administering State plans under this title and a national panel of pediatric, pediatric specialty, and pediatric subspecialty experts.

“(2) Enhanced pediatric health home (EHH); EHH services; EHH program agreement.—

“(A) In general.—The terms ‘enhanced pediatric health home’ and ‘EHH’ mean a provider-sponsored entity qualified to care for children with medically complex conditions that—

“(i) satisfies the requirements of subparagraph (B);

“(ii) has entered into an EHH program agreement (as defined in subparagraph (D)) with a State; and

“(iii) provides or arranges for the provision of EHH services (as defined in
subparagraph (C)) to children with complex medical conditions.

“(B) REQUIREMENTS.—The requirements of this subparagraph are that the entity demonstrates to the State with which the entity desires to enter into an EPHH program agreement that it—

“(i) has expertise in providing, integrating, or coordinating prompt care for children with complex medical conditions, including access to pediatric emergency services at all times;

“(ii) shall design an individualized comprehensive pediatric family-centered care plan for each child with complex medical conditions assigned to the entity, and provide seamless pediatric care coordination by a customized care team with a designated team lead for each such child and the child’s family;

“(iii) shall work with the family of each child with complex medical conditions assigned to the entity 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 consistent with family choice and the needs of the child;

“(iv) shall include the families of children with complex medical conditions in the delivery of care and the development, operation, and evaluation of its services;

“(v) shall interact with children with complex medical conditions and their families in a culturally and linguistically appropriate manner;

“(vi) shall provide integration and access to sub-specialized pediatric services and programs for children with complex medical conditions, including the most intensive diagnostic, treatment, and critical care levels as medically necessary, including appropriate out-of-State care;

“(vii) can 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 providers offering specialized services, such as rehabilitative and habilitative health care and private-duty nursing, if needed;

“(viii) can coordinate the provision of outpatient care needs, including durable medical equipment, medical supplies, and medical foods, if needed;

“(ix) can arrange 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 accordance with the guidance provided under subsection (d)(1);

“(x) can coordinate and collect payments by liable third parties (including parties described in section 1902(a)(25)(A)) for care and services provided or arranged for by the entity; and

“(xi) can collect and report on pediatric quality measures appropriate for chil-
children with medically complex conditions as described in subsection (f)(1).

“(C) EPHH SERVICES.—

“(i) IN GENERAL.—The term ‘EPHH services’ means timely, high-quality pediatric services that are provided to children with complex medical conditions by an enhanced pediatric health home under an EPHH program agreement, including all services for which medical assistance is available under the State plan under this title of the State that is a party to the agreement (or an amendment to such plan) and the services described in clause (ii).

“(ii) SERVICES DESCRIBED.—The services described in this subparagraph are the following:

“(I) Comprehensive pediatric care management, including inpatient and outpatient hospital services, oral health, behavioral health, and, where necessary, hospice care or other long-term services and supports as defined by the State.
“(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.

“(VII) Coordinating access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-State providers, as medically necessary.

“(D) EPHH PROGRAM AGREEMENT.—The term ‘EPHH program agreement’ means an agreement between a State and an EPHH that—

“(i) requires the EPHH to provide, or arrange for or coordinate the provision of, at a minimum, the services described in clause (ii) of subparagraph (C);
“(ii) requires the EPHH to carry out the requirements described in subpara-
graph (B) and comply with the data collec-
tion requirements of subsection (f);

“(iii) provides that the State, with re-
spect to children with complex medical con-
ditions who are residents of the State and are assigned to the EPHH, shall establish policies and procedures for making pay-
ments to the EPHH for providing, arrang-
ing for, or coordinating EPHH services furnished to such children in another State;

“(iv) is subject to all relevant require-
ments imposed by Federal, State, and local law; and

“(v) contains such additional terms and conditions, not inconsistent with this section, as the parties may agree to.

“(3) STATE ADMINISTERING AGENCY.—The term ‘State administering agency’ means the State agency (which shall be the State agency responsible for administering the State plan under this title or the State agency responsible for administering the State program under title V) responsible for admin-
istering EPHH program agreements under this section.

“(c) Family Preference for an Enhanced Pediatric Health Home.—

“(1) In General.—

“(A) Option to Request Enrollment.—Each child with complex medical conditions who is eligible to receive EPHH services under a State plan amendment under this section shall have the option of requesting to be enrolled with an EPHH of the child’s choice in accordance with a process established by the State.

“(B) Enrollment Requirement.—An EPHH shall enroll any child with complex medical conditions who requests enrollment with the EPHH under subparagraph (A) unless the terms of the EPHH program agreement between the EPHH and the State allow the EPHH to decline the child’s request on the basis of pre-established criteria specified in the agreement.

“(2) Outreach and Education.—Each State with a State plan amendment under this section shall conduct outreach and education activities to
raise awareness among children with complex med-
ical conditions and their families of the option to en-
roll in an EPHH and may provide assistance to such
children and their families in making decisions with
respect to such enrollment. The activities and assist-
ance described in this paragraph may include activi-
ties and assistance carried out by—

“(A) family-to-family information centers
under section 501(c);

“(B) family navigators;

“(C) nonprofit organizations; and

“(D) faith-based organizations.

“(3) OPTION TO WITHDRAW FROM PROGRAM.—

“(A) IN GENERAL.—Any child with com-
plex medical conditions that opts into an en-
hanced pediatric health home under this sub-
section shall have the option to disenroll from
the home and to receive covered services under
the State plan under this title or the State child
health plan under title XXI.

“(B) EFFECTIVE DATE OF
DISENROLLMENT.—The disenrollment of a child
with complex medical conditions from an
enhanced pediatric health home shall take effect
not later than 30 days after the child notifies
the health home of the child’s desire to
disenroll.

“(4) TRANSITION ASSISTANCE.—In the case of
an individual who is enrolled in an enhanced pedi-
atriic health home under this section and whose en-
rollment ceases for any reason (including that the
individual no longer qualifies as a child with complex
medical conditions, the termination of an EPHH
program agreement, or otherwise), the enhanced pe-
diatric health home shall continue to provide EPHH
services to the individual during a transition period
to ensure that the individual’s care is not com-
promised, help the individual and the individual’s
family self-manage the individual’s medical condi-
tions to the maximum extent practicable, and pro-
vide assistance to the individual and the individual’s
family in obtaining necessary transitional care
through appropriate referrals and making the indi-
vidual’s medical records available to new providers.

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

“(1) GUIDANCE.—

“(A) IN GENERAL.—Not later than 2 years
after the date of the enactment of this section,
the Secretary shall issue guidance to State
Medicaid Directors on best practices for ensuring that children with complex medical conditions receive prompt care from out-of-State providers when medically necessary, including guidance regarding—

“(i) arranging access to, and providing payment for, care for such children provided by out-of-State providers;

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

“(iii) screening and enrolling out-of-State providers, including efforts to streamline the process or reduce the burden on out-of-State providers that do not regularly treat children from the State or that only treat a small number of children from the State (which may include providing for payment to such a provider without requiring the provider to enroll in the State plan);

“(iv) providing for payment to out-of-State providers that provide care for children with complex medical conditions in
emergency and non-emergency situations;

and

“(v) how the guidance provided under
this subparagraph interacts with the re-
quirements of section 431.52 of title 42,
Code of Federal Regulations.

“(B) STAKEHOLDER INPUT.—In carrying
out subparagraph (A), the Secretary shall issue
a Request For Information to seek input from
States, patient or family advocates and organi-
izations that represent patients or families, chil-
dren’s health groups, providers (including chil-
dren’s hospitals, hospitals, pediatricians, and
other pediatric providers), managed care plans,
and other relevant stakeholders.

“(2) OUT-OF-STATE POLICIES FOR EPHHS.—A
State electing to provide medical assistance pursuant
to subsection (a) shall provide information, con-
sistent with guidance from the Secretary, to en-
hanced pediatric health homes receiving payment
under this section, regarding the State’s policies and
procedures for accessing care for children with com-
plex medical conditions from out-of-State providers.
For the purpose of helping facilitate medically nec-
essary care for such children, such information shall
include information on how out-of-State providers
who provide services to such children can receive
payment by such State Medicaid program.

“(3) **BEST PRACTICES.**—A State electing to
provide medical assistance pursuant to subsection
(a) shall consider adopting best practices for pro-
viding access to out-of-State providers for children
with complex medical conditions consistent with
guidance provided by the Secretary under paragraph
(1).

“(e) **PAYMENTS TO ENHANCED PEDIATRIC HEALTH**
HOMES.—

“(1) **IN GENERAL.**—A State shall provide an
EPHH with payments for the provision of EPHH
services to each child enrolled with an EPHH that
has an EPHH program agreement with the State.
Such payments for such services shall be treated in
the same manner as payments under section
1945(c)(1), and, with respect to payments for serv-
ices described in section 1945(h)(4)(B) provided by
an EPHH to children with complex medical condi-
tions enrolled with the EPHH during the first 8 fis-
cal quarters in which the EPHH program agreement
is in effect, the Federal medical assistance percent-
age applicable to such payments shall be equal to
the Federal medical assistance percentage specified in section 1945(c)(1).

“(2) ALTERNATIVE PAYMENT MODEL METHODOLOGY.—Payment to enhanced pediatric health homes for EPHH services furnished pursuant to a EPHH program agreement shall be made in a manner to be determined by the State using an agreed-upon alternative payment methodology developed under paragraph (4).

“(3) CMS GUIDANCE ON ALTERNATIVE PAYMENT MODEL METHODOLOGIES.—

“(A) IN GENERAL.—Not later than January 1, 2018, the Secretary shall publish guidance describing best practices for States to employ in designing and establishing alternative payment model methodologies which may be used by enhanced pediatric health homes with EPHH program agreements in developing equitable, alternative payment model methodologies for EPHH programs under paragraph (4). The guidance shall include descriptions of best practices related to designing shared savings and performance-based payment models that are risk-adjusted for the population enrolled in EPHH programs, and may include guidance re-
lated to other alternative payment models, including global payments and bundled payments.

“(B) Stakeholder Input.—In carrying out subparagraph (A), the Secretary shall issue a Request for Information to seek input from States, the Medicaid and CHIP Payment and Access Commission, providers (including children’s hospitals, hospitals, pediatricians, and other pediatric providers), managed care plans, children’s health groups, family and beneficiary advocates, the pediatric health care community, and other relevant stakeholders.

“(C) Data Analysis.—Beginning in the first year of the implementation of enhanced pediatric health homes, the Secretary shall analyze, for purposes of developing the guidance required under this paragraph—

“(i) data collected under subsection (f)(1); and

“(ii) other data as the Secretary determines appropriate.

“(4) Development of Alternative Payment Model Methodology.—

“(A) In General.—Each State, in collaboration with any enhanced pediatric health
home that is operating an EPHH program under this section in the State, shall develop the payment methodology or methodologies for payment under the State plan in accordance with this subsection that—

“(i) includes—

“(I) a risk adjustment method, re-insurance system, or risk-corridor procedure to account for variations in acuity of the children with complex medical conditions enrolled in enhanced pediatric health homes; and

“(II) an alternative payment model, which may include a shared savings approach or performance-based approach, such as a bundled payment or risk-reward payment model;

“(ii) may be informed by guidance published by the Secretary under paragraph (3)(A); and

“(iii) considers data analyzed under paragraph (3)(C), to the maximum extent practicable.
“(B) Approval by state Medicaid agency required.—No payment may be made under a payment methodology developed under this paragraph unless—

“(i) the relevant State agency responsible for administering the State plan under this title has approved such methodology; and

“(ii) the methodology is described in a State plan amendment that has received approval from the Secretary.

“(f) Data and quality assurance.—

“(1) Data.—The data collection requirements under this paragraph, with respect to an enhanced pediatric health home, are as follows:

“(A) The home, in collaboration with the State and the child’s health plan if appropriate, shall collect and submit claims data on claims submitted with respect to children who are furnished EPHH services. After approval by the State, such data shall be reported in a standardized format in a timely manner and made available to the public for the purposes of establishing a national database on such claims.
“(B) The State shall submit to the Secretary such reports as the Secretary finds necessary to monitor the operation, cost, and effectiveness of the EPHH services furnished by the home.

“(2) DEVELOPMENT OF STANDARDS AND MEASURES.—The Secretary shall, in consultation with States and enhanced pediatric health homes with EPHH program agreements under this section and national pediatric policy organizations—

“(A) establish a national set of quality assurance and improvement protocols and procedures to apply under EPHH programs established under this section;

“(B) develop pediatric quality measures that are tailored to the care and treatment of children with complex medical conditions and account for the health and well-being, care coordination, child and family experience, and access to and cost of care for children with complex medical conditions;

“(C) develop provider accessibility standards for access by children with complex medical conditions to EPHH services; and
“(D) develop criteria for national pediatric-focused care coordination for children with complex medical conditions.

“(3) Use of existing quality measures.—In carrying out paragraph (2), the Secretary shall consider incorporating, to the extent applicable, the following measures:

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

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

“(C) Other existing quality measures, as considered appropriate by the Secretary.

“(4) National pediatric policy organizations.—For purposes of paragraph (2), the national pediatric policy organizations that the Secretary shall consult with shall include the following:

“(A) Acute care children’s hospitals.

“(B) Specialty pediatric hospitals.

“(C) Subacute, rehabilitative, and long-term care pediatric hospitals.
“(D) Pediatric providers, including primary care providers, specialists, and subspecialists.

“(E) Pediatric home, community, and family care organizations, including organizations representing families or children with special needs.

“(F) National pediatric policy organizations with specific expertise relating to children with complex medical conditions.

“(G) Such other entities as the Secretary shall determine appropriate.

“(5) STANDARD MEDICAID DATA SET.—

“(A) IN GENERAL.—The Secretary, the States, and the enhanced pediatric health homes with EPHH program agreements under this section shall collaborate to obtain consistent and verifiable Medicaid Analytic Extract data or a comparable data set and shall establish data-sharing agreements to further support collaborative planning and care coordination for children with complex medical conditions.

“(B) CLAIMS ANALYSIS.—

“(i) ANALYSIS BY INDEPENDENT THIRD PARTY.—The Secretary shall com-
mission an independent third party to perform claims analysis on the data set developed under subparagraph (A) to determine the utilization of items and services furnished under EPHH programs to children with complex medical conditions, and the overall effectiveness of EPHH programs.

“(ii) REPORT.—For purposes of building a national database, the Secretary shall submit to Congress, and make publicly available on the Internet site of the Centers for Medicare & Medicaid Services, a report on the analysis carried out under clause (i).”.

(b) Application Under CHIP.—Section 2107(e)(1) of the Social Security Act (42 U.S.C. 1397gg(e)(1)) is amended by adding at the end the following new subparagraph:

“(P) Section 1947 (relating to the Medicaid EPHH program for children with complex medical conditions).”.

SEC. 3. 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 a report to Congress and the Secretary of Health and Human Services on children with complex medical conditions 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 complex medical 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 complex medical 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, serious injuries, 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 and the type of payment model being used; and

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

(3) The pediatric providers who serve children with complex medical conditions.

(4) The extent to which children with complex medical conditions receive or are denied 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.

SEC. 4. REPORT TO CONGRESS.

Not later than 5 years after the date of the enactment of this Act, the Secretary of Health and Human Services shall submit Congress, and make publicly available on the Internet site of the Centers for Medicare & Medicaid Services, a report evaluating and assessing the
enhanced pediatric health home program established under section 1947 of the Social Security Act (as added by section 2), for the purposes of determining—

(1) how the program might be improved; and

(2) whether the program should be expanded to include pediatric populations that are not children with complex medical conditions (as such term is defined for purposes of the program) but who would still benefit from the type of care coordination provided by an enhanced pediatric health home.