

115TH CONGRESS
1ST SESSION

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”.

1 **SEC. 2. ESTABLISHMENT OF STATE MEDICAID OPTION TO**
2 **PROVIDE COORDINATED CARE THROUGH A**
3 **HEALTH HOME FOR CHILDREN WITH COM-**
4 **PLEX MEDICAL CONDITIONS.**

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

8 “STATE OPTION TO PROVIDE COORDINATED CARE
9 THROUGH A HEALTH HOME FOR CHILDREN WITH
10 COMPLEX MEDICAL CONDITIONS

11 “SEC. 1947. (a) IN GENERAL.—Notwithstanding sec-
12 tion 1902(a)(1) (relating to statewideness), section
13 1902(a)(10)(B) (relating to comparability), section
14 1902(a)(23) (relating to freedom of choice), section
15 1902(a)(30)(A) (relating to equal access), and any other
16 provision of this title which the Secretary determines it
17 is necessary to waive in order to implement this section
18 (other than section 1905(a)(4)(B) (relating to early and
19 periodic screening, diagnostic, and treatment services)),
20 beginning on January 1, 2018, a State, at its option as
21 a State plan amendment, may provide for medical assist-
22 ance under this title to children with medically complex
23 conditions who select (or for whom is selected) a des-
24 ignated provider, or a team of health care professionals,
25 as the individual’s health home for purposes of providing
26 such children with health home services.

1 “(b) PAYMENTS.—

2 “(1) IN GENERAL.—A State shall provide, with
3 respect to health home services furnished to each
4 child with medically complex conditions who selects
5 or for whom there is selected a designated provider
6 or a team as the child’s health home pursuant to
7 this section, to such designated provider or team
8 with payments for the provision of such health home
9 services. The State shall make such payments re-
10 gardless of whether a child with medically complex
11 conditions described in the preceding sentence re-
12 ceives health home services under this section
13 through a fee-for-service or managed care system.
14 Such payments for such services shall be treated as
15 medical assistance (as defined in section 1905(a))
16 for purposes of payments made under section
17 1903(a), except that, during the first 8 fiscal year
18 quarters that the State plan amendment is in effect,
19 the Federal medical assistance percentage applicable
20 to such payments shall be increased by 20 percent-
21 age points, but in no case shall exceed 90 percent.

22 “(2) METHODOLOGY.—

23 “(A) IN GENERAL.—The State shall speci-
24 fy in the State plan amendment the method-
25 ology the State will use for determining pay-

1 ment under paragraph (1). Such methodology
2 for determining payment—

3 “(i) may be tiered to reflect, with re-
4 spect to each child with medically complex
5 conditions and each designated provider, or
6 team of health care professionals, the se-
7 verity or number of such child’s chronic
8 conditions, life-threatening illnesses, dis-
9 abilities, or rare diseases or the specific ca-
10 pabilities of such provider or such team;

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

13 “(iii) shall take into account any feed-
14 back the State receives from stakeholders.

15 “(B) MODELS OF PAYMENT.—The method-
16 ology under subparagraph (A) may include pay-
17 ments made on a per-member, per-month basis
18 and may include shared savings models, pay-
19 for-performance models, contingency awards de-
20 pendent on reducing utilization of emergency
21 departments, or other incentive-based ap-
22 proaches, as defined by the State.

23 “(C) ENSURING HIGH-QUALITY CARE.—
24 The methodology under subparagraph (A) shall
25 include the State’s strategy for evaluating the

1 quality of care provided within a health home
2 pursuant to this section. Such strategy shall
3 take into account the following quality meas-
4 ures that may be applicable for health homes
5 that serve children with medically complex con-
6 ditions:

7 “(i) Child health quality measures and
8 measures for centers of excellence for chil-
9 dren with complex needs developed under
10 this title, title XXI, and section 1139A.

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

13 “(iii) The health home’s expertise in
14 providing, integrating, or coordinating
15 prompt care for children with complex
16 medical conditions, including access to pe-
17 diatric emergency services at all times.

18 “(iv) The health home’s ability to co-
19 ordinate and integrate the full range of pe-
20 diatric medical, surgical, and behavioral
21 specialists and subspecialists needed, based
22 on clinical qualifications (such as board
23 certification) and patient preference on the
24 care team to care for children with com-
25 plex medical conditions, as well as pro-

1 viders offering specialized services, such as
2 rehabilitative and habilitative health care
3 and private-duty nursing, if needed.

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

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

19 “(vii) The health home’s ability to co-
20 ordinate and collect payments from liable
21 third parties (including parties described in
22 section 1902(a)(25)(A)) for care and serv-
23 ices provided or arranged for by the entity.

1 “(viii) The health home’s ability to
2 collect and report on the information re-
3 quired under subsection (d)(1).

4 “(c) COORDINATING CARE.—

5 “(1) HOSPITAL REFERRALS.—A State shall in-
6 clude in the State plan amendment under this sec-
7 tion—

8 “(A) a requirement for hospitals partici-
9 pating under the State plan under this title or
10 a waiver of such plan to establish procedures
11 for hospital emergency departments to refer
12 children with medically complex conditions en-
13 rolled in a health home pursuant to this section
14 to designated providers or teams of health care
15 professionals who are participating in such
16 health home; and

17 “(B) a requirement for the State to notify
18 such hospitals of any designated providers or
19 teams of health care professionals who are par-
20 ticipating in a health home.

21 “(2) EDUCATION WITH RESPECT TO AVAIL-
22 ABILITY OF HEALTH HOME SERVICES.—A State
23 shall include in the State plan amendment under
24 this section a description of the State’s process for
25 educating providers participating in the State plan

1 under this title or a waiver of such plan about the
2 availability of health home services for children with
3 medically complex conditions, including the process
4 by which such providers can refer such children to
5 designated providers (or a team of health care pro-
6 fessionals) to receive such services.

7 “(3) FAMILY EDUCATION.—A State shall in-
8 clude in the State plan amendment under this sec-
9 tion a description of the State’s process for edu-
10 cating families with children eligible to receive health
11 home services pursuant to this section of the avail-
12 ability of such services. Such process may include
13 the participation of family-to-family entities or other
14 public or private organizations or entities who pro-
15 vide outreach and information about the availability
16 of health care items and services to families of indi-
17 viduals eligible to receive medical assistance under
18 the State plan under this title (or a waiver of the
19 plan).

20 “(4) COORDINATING CARE FROM OUT-OF-STATE
21 PROVIDERS.—

22 “(A) IN GENERAL.—A State electing to
23 provide medical assistance pursuant to sub-
24 section (a) shall provide guidance, consistent
25 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-

1 ices shall make available on a public Internet
2 website of the Centers for Medicare & Medicaid
3 Services a list of the States with a State plan
4 amendment approved under this section and the
5 degree to which (as determined by the Adminis-
6 trator) such States have adopted the best prac-
7 tices recommended by the Administrator in
8 such guidance.

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

17 “(D) FAILURE TO IMPLEMENT BEST PRAC-
18 TICES.—Beginning 180 days after the date on
19 which guidance is issued by the Administrator
20 of the Centers for Medicare & Medicaid Serv-
21 ices pursuant to section 4 of the ACE Kids Act,
22 in the case of a State with a State plan amend-
23 ment approved under this section that the Ad-
24 ministrator of the Centers for Medicare & Med-
25 icaid Services determines has not adopted the

1 best practices recommended by the Adminis-
2 trator in such guidance, the increase of the
3 Federal medical assistance percentage applied
4 under subsection (b)(1) shall be reduced by 10
5 percentage points.

6 “(d) DATA COLLECTION.—

7 “(1) PROVIDER REPORTING REQUIREMENTS.—

8 As a condition of receiving payment under this sec-
9 tion, a designated provider or team of health care
10 professionals receiving payment for health home
11 services under this section shall report to the State
12 the following information:

13 “(A) With respect to each such provider or
14 team, the name, National Provider Identifica-
15 tion number, address, and specific health care
16 services offered to be provided to children with
17 medically complex conditions enrolled in the
18 health home involved.

19 “(B) Information on all applicable meas-
20 ures used by such provider or team for pur-
21 poses of assisting in assessing the quality and
22 effectiveness of such services.

23 “(C) Other such information as the Ad-
24 ministrator of the Centers for Medicare & Med-
25 icaid Services shall specify in guidance.

1 “(2) STATE REPORTING REQUIREMENTS.—A
2 State electing to provide medical assistance pursuant
3 to subsection (a) shall collect and provide to the Ad-
4 ministrator of the Centers for Medicare & Medicaid
5 Services (and to the Medicaid and CHIP Payment
6 and Access Commission upon request), in a form
7 and manner determined by the Administrator to be
8 reasonable and minimally burdensome, the following
9 information:

10 “(A) Information reported under para-
11 graph (1).

12 “(B) The number of children with medi-
13 cally complex conditions who have selected a
14 health home or for whom a health home was se-
15 lected pursuant to this section.

16 “(C) The nature, number, and prevalence
17 of chronic conditions, life-threatening illnesses,
18 disabilities, or rare diseases that such children
19 have.

20 “(D) The type of delivery systems and pay-
21 ment models used to provide services to such
22 children under this section.

23 “(E) The number and characteristics of
24 providers or health care professionals des-
25 ignated 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—

1 “(I) 1 chronic condition that af-
2 fects three or more organ systems and
3 severely reduces cognitive or physical
4 functioning (such as the ability to eat,
5 drink, or breathe independently) and
6 which also requires the use of medica-
7 tion, durable medical equipment, ther-
8 apy, surgery, or other treatment or
9 treatments; or

10 “(II) 1 life-limiting illness or rare
11 pediatric disease (as defined in section
12 529(a)(3) of the Federal Food, Drug,
13 and Cosmetic Act (21 U.S.C.
14 360fff(a)(3))), such as a form of can-
15 cer.

16 “(B) RULE OF CONSTRUCTION.—Nothing
17 in this paragraph shall prevent a State with a
18 State plan amendment approved under this sec-
19 tion, with respect to determining the eligibility
20 of a children with medically complex conditions
21 to receive health home services under such
22 State plan amendment, from increasing the
23 number or severity of chronic conditions, life-
24 threatening illnesses, disabilities, or rare dis-
25 eases.

1 “(2) CHRONIC CONDITION.—The term ‘chronic
2 condition’ means a serious, long-term physical, men-
3 tal, or developmental disability or disease, such as
4 any of the following:

5 “(A) Cerebral palsy.

6 “(B) Cystic fibrosis.

7 “(C) HIV/AIDS.

8 “(D) Blood diseases, such as anemia or
9 sickle cell disease.

10 “(E) Muscular dystrophy.

11 “(F) Spina bifida.

12 “(G) Epilepsy.

13 “(H) Severe autism spectrum disorder.

14 “(I) Serious emotional disturbance or seri-
15 ous mental health illness.

16 “(3) HEALTH HOME.—The term ‘health home’
17 means a designated provider or a team of health
18 care professionals selected to provide health home
19 services to a child with medically complex conditions.

20 “(4) HEALTH HOME SERVICES.—

21 “(A) IN GENERAL.—The term ‘health
22 home services’ means the services described in
23 subparagraph (B) that are provided by a des-
24 ignated provider, or a team of health care pro-

1 professionals in a timely manner and on a high-
2 quality basis.

3 “(B) SERVICES DESCRIBED.—The services
4 described in this subparagraph shall, at a min-
5 imum, include—

6 “(i) an individualized comprehensive
7 pediatric family-centered care plan for each
8 child with complex medical conditions as-
9 signed to the health home that provides
10 seamless pediatric care coordination by a
11 customized care team with a designated
12 team lead for each such child and the
13 child’s family;

14 “(ii) care coordination, health pro-
15 motion, and providing access to the full
16 range of pediatric specialty and sub-
17 specialty medical services, including early
18 and periodic screening, diagnostic, and
19 treatment services described in section
20 1905(a)(4)(B) and services from out-of-
21 State providers, as medically necessary;

22 “(iii) comprehensive transitional care,
23 including appropriate follow-up, from inpa-
24 tient to other settings;

1 “(iv) working with the family of each
2 child with complex medical conditions as-
3 signed to the health home to develop and
4 incorporate ongoing home care, community
5 based pediatric primary care, care from the
6 most medically appropriate or family-pre-
7 ferred children’s hospital, social support
8 services, and local hospital pediatric emer-
9 gency care into the child’s care plan, to the
10 extent consistent with family choice and
11 the needs of the child;

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

14 “(vi) use of health information tech-
15 nology to link services, as feasible and ap-
16 propriate;

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

22 “(viii) efforts to include, with respect
23 to the delivery of care and the develop-
24 ment, operation, and evaluation of the

1 health home's services, the families of chil-
2 dren with complex medical conditions;

3 “(ix) ensuring that any interactions
4 with each child with complex medical con-
5 ditions and the child's family occurs in a
6 culturally and linguistically appropriate
7 manner; and

8 “(x) providing integration with, and
9 access to, subspecialized pediatric services
10 and programs for children with complex
11 medical conditions, including the most in-
12 tensive diagnostic, treatment, and critical
13 care levels as medically necessary and ap-
14 propriate out-of-State care.

15 “(5) DESIGNATED PROVIDER.—The term ‘des-
16 ignated provider’ means a physician (including a pe-
17 diatrician or a pediatric specialty or subspecialty
18 provider), children's hospital, clinical practice or
19 clinical group practice, prepaid inpatient health plan
20 or prepaid ambulatory health plan (as defined by the
21 Secretary of Health and Human Services), rural
22 clinic, community health center, community mental
23 health center, home health agency, or any other enti-
24 ty or provider that is determined by the State and
25 approved by the Administrator of the Centers for

1 Medicare & Medicaid Services to be qualified to be
2 a health home for children with medically complex
3 conditions on the basis of documentation evidencing
4 that the entity has the systems, expertise, and infra-
5 structure in place to provide health home services.
6 Such term may include providers who are employed
7 by, or affiliated with, a children’s hospital.

8 “(6) TEAM OF HEALTH CARE PROFES-
9 SIONALS.—

10 “(A) IN GENERAL.—The term ‘team of
11 health care professionals’ means a team of
12 health care professionals (as described in the
13 State plan amendment under this section) that
14 may—

15 “(i) include physicians and other pro-
16 fessionals, such as pediatricians or pedi-
17 atric specialty or subspecialty providers,
18 nurse care coordinators, dietitians, nutri-
19 tionists, social workers, behavioral health
20 professionals, physical therapists, occupa-
21 tional therapists, speech pathologists,
22 nurses, individuals with experience in med-
23 ical supportive technologies, or any profes-
24 sionals determined to be appropriate by the
25 State and approved by the Administrator

1 of the Centers for Medicare & Medicaid
2 Services; and

3 “(ii) be free standing, virtual, or
4 based at a children’s hospital, hospital,
5 community health center, community men-
6 tal health center, rural clinic, clinical prac-
7 tice or clinical group practice, academic
8 health center, or any entity determined to
9 be appropriate by the State and approved
10 by the Administrator of the Centers for
11 Medicare & Medicaid Services.

12 “(B) INCLUSION.—Such term includes—

13 “(i) an entity or individual who is des-
14 ignated to coordinate such team; and

15 “(ii) community health workers,
16 translators, and other individuals with cul-
17 turally-appropriate expertise.”.

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

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

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

3 (a) IN GENERAL.—Not later than one year after the
4 date of the enactment of this Act, the Administrator of
5 the Centers for Medicare & Medicaid Services shall issue
6 guidance to State Medicaid Directors on best practices for
7 using out-of-State providers to provide care to children
8 with medically complex conditions (as defined in section
9 1947 of the Social Security Act, as added by section 2
10 of this Act), including guidance regarding—

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

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

17 (3) processes for screening and enrolling such
18 providers in the State plan under title XIX of the
19 Social Security Act (or a waiver of the plan), includ-
20 ing efforts to streamline such processes or reduce
21 the burden of such processes on providers.

22 (b) STAKEHOLDER INPUT.—In carrying out sub-
23 section (a), the Administrator of the Centers for Medicare
24 & Medicaid Services shall issue a request for information
25 to seek input from children with medically complex condi-
26 tions (as defined in section 1947 of the Social Security

1 Act, as added by section 2 of this Act) and their families,
2 States, providers (including children's hospitals, hospitals,
3 pediatricians, and other providers), managed care plans,
4 children's health groups, family and beneficiary advocates,
5 and other stakeholders with respect to coordinating the
6 care for such children furnished by out-of-State providers.

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

16 **SEC. 5. MACPAC REPORT.**

17 (a) IN GENERAL.—Not later than 24 months after
18 the date of the enactment of this Act, the Medicaid and
19 CHIP Payment and Access Commission established under
20 section 1900 of the Social Security Act (42 U.S.C. 1396)
21 shall submit to Congress and the Secretary of Health and
22 Human Services a report on children with medically com-
23 plex conditions that—

24 (1) describes options for defining the character-
25 istics of such children;

1 (2) includes the information described in sub-
2 section (b); and

3 (3) includes such recommendations as the Com-
4 mission determines is appropriate.

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

8 (1) With respect to the characteristics of chil-
9 dren with medically complex conditions (as defined
10 in section 1947 of the Social Security Act (as added
11 by section 2 of this Act))—

12 (A) a literature review examining—

13 (i) research on such children;

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

17 (iii) demographic characteristics, in-
18 cluding primary language, based on avail-
19 able data; and

20 (B) information gathered from consulta-
21 tion with medical and academic experts engaged
22 in research about, or the treatment of, such
23 children.

24 (2) Information relating to children with medi-
25 cally complex conditions who are receiving medical

1 assistance under a State Medicaid plan under title
2 XIX of the Social Security Act (or a waiver of such
3 plan), including—

4 (A) the number of such children;

5 (B) the chronic conditions, life-threatening
6 illnesses, disabilities, injuries, or rare diseases
7 that such children have;

8 (C) the number of such children receiving
9 services under each delivery system or payment
10 model, including health homes (as defined in
11 such section 1947), fee-for-service systems, pri-
12 mary care case managers, or managed care
13 plans; and

14 (D) the extent to which such children re-
15 ceive care coordination services.

16 (3) Information on the providers who furnish
17 health care items and services to children with medi-
18 cally complex conditions, such as physicians (includ-
19 ing pediatricians and pediatric specialty or sub-
20 specialty providers), children's hospitals, clinical
21 practices or clinical group practices, rural clinics,
22 community health centers, community mental health
23 centers, or home health agencies.

24 (4) The extent to which children with medically
25 complex conditions receive (or are denied) health

1 care items and services from out-of-State providers
2 that receive payment under the State Medicaid plan
3 under title XIX of the Social Security Act (or a
4 waiver of such plan) and any barriers to receiving
5 such services from such providers in a timely fash-
6 ion, including any variation in access to such serv-
7 ices furnished by such providers, disaggregated by
8 delivery system.

9 (5) The amount and nature of the total re-
10 sources used to provide care to individual children
11 with medically complex conditions during the period
12 in which such a child is enrolled in a health home,
13 including—

14 (A) the amount of capital spent in pro-
15 viding such care;

16 (B) the resources used to provide such care
17 during any waiting period with respect to the
18 enrollment of the child in the State plan under
19 title XIX of the Social Security Act (or a waiv-
20 er of such plan) or any necessary approval
21 under the State plan for the furnishing of such
22 services (such as inpatient costs awaiting dis-
23 charge);

24 (C) the cost of the coordination of such
25 child's care;

1 (D) the cost of providing to such child any
2 non-medical benefits (such as transportation
3 and home services); and

4 (E) the clinical costs of providing such
5 care.

○