

116TH CONGRESS
1ST SESSION

H. R. 1226

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 14, 2019

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

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.

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 2019” or the “ACE Kids Act of
6 2019”.

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

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

7 **“SEC. 1945A. STATE OPTION TO PROVIDE COORDINATED**
 8 **CARE THROUGH A HEALTH HOME FOR CHIL-**
 9 **DREN WITH MEDICALLY COMPLEX CONDI-**
 10 **TIONS.**

11 “(a) IN GENERAL.—Notwithstanding section
 12 1902(a)(1) (relating to statewideness) and section
 13 1902(a)(10)(B) (relating to comparability), beginning Oc-
 14 tober 1, 2022, a State, at its option as a State plan
 15 amendment, may provide for medical assistance under this
 16 title to children with medically complex conditions who
 17 choose to enroll in a health home under this section by
 18 selecting a designated provider, a team of health care pro-
 19 fessionals operating with such a provider, or a health team
 20 as the child’s health home for purposes of providing the
 21 child with health home services.

22 “(b) HEALTH HOME QUALIFICATION STANDARDS.—
 23 The Secretary shall establish standards for qualification
 24 as a health home for purposes of this section. Such stand-
 25 ards shall include requiring designated providers, teams
 26 of health care professionals operating with such providers,

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

3 “(1) Coordinate prompt care for children with
4 medically complex conditions, including access to pe-
5 diatric emergency services at all times.

6 “(2) Develop an individualized comprehensive
7 pediatric family-centered care plan for children with
8 medically complex conditions that accommodates pa-
9 tient preferences.

10 “(3) Work in a culturally and linguistically ap-
11 propriate manner with the family of a child with
12 medically complex conditions to develop and incor-
13 porate into such child’s care plan, in a manner con-
14 sistent with the needs of the child and the choices
15 of the child’s family, ongoing home care, community-
16 based pediatric primary care, pediatric inpatient
17 care, social support services, and local hospital pedi-
18 atric emergency care.

19 “(4) Coordinate access to—

20 “(A) subspecialized pediatric services and
21 programs for children with medically complex
22 conditions, including the most intensive diag-
23 nostic, treatment, and critical care levels as
24 medically necessary; and

1 “(B) palliative services if the State pro-
2 vides such services under the State plan (or a
3 waiver of such plan).

4 “(5) Coordinate care for children with medically
5 complex conditions with out-of-State providers fur-
6 nishing care to such children to the maximum extent
7 practicable for the families of such children and
8 where medically necessary, in accordance with guid-
9 ance issued under subsection (e)(1) and section
10 431.52 of title 42, Code of Federal Regulations.

11 “(6) Collect and report information under sub-
12 section (g)(1).

13 “(c) PAYMENTS.—

14 “(1) IN GENERAL.—A State shall provide a des-
15 ignated provider, a team of health care professionals
16 operating with such a provider, or a health team
17 with payments for the provision of health home serv-
18 ices to each child with medically complex conditions
19 that selects such provider, team of health care pro-
20 fessionals, or health team as the child’s health home.
21 Payments made to a designated provider, a team of
22 health care professionals operating with such a pro-
23 vider, or a health team for such services shall be
24 treated as medical assistance for purposes of section
25 1903(a), except that, during the first 2 fiscal year

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

5 “(2) METHODOLOGY.—

6 “(A) IN GENERAL.—The State shall speci-
7 fy in the State plan amendment the method-
8 ology the State will use for determining pay-
9 ment for the provision of health home services.
10 Such methodology for determining payment—

11 “(i) may be tiered to reflect, with re-
12 spect to each child with medically complex
13 conditions provided such services by a des-
14 ignated provider, a team of health care
15 professionals operating with such a pro-
16 vider, or a health team, the severity or
17 number of each such child’s chronic condi-
18 tions, life-threatening illnesses, disabilities,
19 or rare diseases, or the specific capabilities
20 of the provider, team of health care profes-
21 sionals, or health team; and

22 “(ii) shall be established consistent
23 with section 1902(a)(30)(A).

24 “(B) ALTERNATE MODELS OF PAYMENT.—

25 The methodology for determining payment for

1 provision of health home services under this
2 section shall not be limited to a per-member
3 per-month basis and may provide (as proposed
4 by the State and subject to approval by the
5 Secretary) for alternate models of payment.

6 “(3) PLANNING GRANTS.—

7 “(A) IN GENERAL.—Beginning October 1,
8 2022, the Secretary may award planning grants
9 to States for purposes of developing a State
10 plan amendment under this section. A planning
11 grant awarded to a State under this paragraph
12 shall remain available until expended.

13 “(B) STATE CONTRIBUTION.—A State
14 awarded a planning grant shall contribute an
15 amount equal to the State percentage deter-
16 mined under section 1905(b) (without regard to
17 section 5001 of Public Law 111–5) for each fis-
18 cal year for which the grant is awarded.

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

22 “(d) COORDINATING CARE.—

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

1 provider under the State plan (or a waiver of such
2 plan) to establish procedures for, in the case of a
3 child with medically complex conditions who is en-
4 rolled in a health home pursuant to this section and
5 seeks treatment in the emergency department of
6 such hospital, notifying the health home of such
7 child of such treatment.

8 “(2) EDUCATION WITH RESPECT TO AVAIL-
9 ABILITY OF HEALTH HOME SERVICES.—In order for
10 a State plan amendment to be approved under this
11 section, a State shall include in the State plan
12 amendment a description of the State’s process for
13 educating providers participating in the State plan
14 (or a waiver of such plan) on the availability of
15 health home services for children with medically
16 complex conditions, including the process by which
17 such providers can refer such children to a des-
18 ignated provider, team of health care professionals
19 operating such a provider, or health team for the
20 purpose of establishing a health home through which
21 such children may receive such services.

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

1 families with children eligible to receive health home
2 services pursuant to this section of the availability of
3 such services. Such process shall include the partici-
4 pation of family-to-family entities or other public or
5 private organizations or entities who provide out-
6 reach and information on the availability of health
7 care items and services to families of individuals eli-
8 gible to receive medical assistance under the State
9 plan (or a waiver of such plan).

10 “(4) MENTAL HEALTH COORDINATION.—A
11 State with a State plan amendment approved under
12 this section shall consult and coordinate, as appro-
13 priate, with the Secretary in addressing issues re-
14 garding the prevention and treatment of mental ill-
15 ness and substance use among children with medi-
16 cally complex conditions receiving health home serv-
17 ices under this section.

18 “(e) GUIDANCE ON COORDINATING CARE FROM
19 OUT-OF-STATE PROVIDERS.—

20 “(1) IN GENERAL.—Not later than October 1,
21 2020, the Secretary shall issue (and update as the
22 Secretary determines necessary) guidance to State
23 Medicaid directors on—

1 “(A) best practices for using out-of-State
2 providers to provide care to children with medi-
3 cally complex conditions;

4 “(B) coordinating care for such children
5 provided by such out-of-State providers (includ-
6 ing when provided in emergency and non-emer-
7 gency situations);

8 “(C) reducing barriers for such children
9 receiving care from such providers in a timely
10 fashion; and

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

16 “(2) STAKEHOLDER INPUT.—In carrying out
17 paragraph (1), the Secretary shall issue a request
18 for information to seek input from children with
19 medically complex conditions and their families,
20 States, providers (including children’s hospitals, hos-
21 pitals, pediatricians, and other providers), managed
22 care plans, children’s health groups, family and ben-
23 eficiary advocates, and other stakeholders with re-
24 spect to coordinating the care for such children pro-
25 vided by out-of-State providers.

1 “(f) MONITORING.—A State shall include in the State
2 plan amendment—

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

7 “(2) a proposal for use of health information
8 technology in providing health home services under
9 this section and improving service delivery and co-
10 ordination across the care continuum (including the
11 use of wireless patient technology to improve coordi-
12 nation and management of care and patient adher-
13 ence to recommendations made by their provider);
14 and

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

19 “(g) DATA COLLECTION.—

20 “(1) PROVIDER REPORTING REQUIREMENTS.—
21 In order to receive payments from a State under
22 subsection (c), a designated provider, a team of
23 health care professionals operating with such a pro-
24 vider, or a health team shall report to the State, at

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

3 “(A) With respect to each such provider,
4 team of health care professionals, or health
5 team, the name, National Provider Identifica-
6 tion number, address, and specific health care
7 services offered to be provided to children with
8 medically complex conditions who have selected
9 such provider, team of health care profes-
10 sionals, or health team as the health home of
11 such children.

12 “(B) Information on all applicable meas-
13 ures for determining the quality of health home
14 services provided by such provider, team of
15 health care professionals, or health team, in-
16 cluding, to the extent applicable, child health
17 quality measures and measures for centers of
18 excellence for children with complex needs de-
19 veloped under this title, title XXI, and section
20 1139A.

21 “(C) Such other information as the Sec-
22 retary shall specify in guidance.

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

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

3 “(2) STATE REPORTING REQUIREMENTS.—

4 “(A) COMPREHENSIVE REPORT.—A State
5 with a State plan amendment approved under
6 this section shall report to the Secretary (and,
7 upon request, to the Medicaid and CHIP Pay-
8 ment and Access Commission), at such time
9 and in such form and manner determined by
10 the Secretary to be reasonable and minimally
11 burdensome, the following information:

12 “(i) Information reported under para-
13 graph (1).

14 “(ii) The number of children with
15 medically complex conditions who have se-
16 lected a health home pursuant to this sec-
17 tion.

18 “(iii) The nature, number, and preva-
19 lence of chronic conditions, life-threatening
20 illnesses, disabilities, or rare diseases that
21 such children have.

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

1 “(v) The number and characteristics
2 of designated providers, teams of health
3 care professionals operating with such pro-
4 viders, and health teams selected as health
5 homes pursuant to this section, including
6 the number and characteristics of out-of-
7 State providers, teams of health care pro-
8 fessionals operating with such providers,
9 and health teams who have provided health
10 care items and services to such children.

11 “(vi) The extent to which such chil-
12 dren receive health care items and services
13 under the State plan.

14 “(vii) Quality measures developed spe-
15 cifically with respect to health care items
16 and services provided to children with
17 medically complex conditions.

18 “(B) REPORT ON BEST PRACTICES.—Not
19 later than 90 days after a State has a State
20 plan amendment approved under this section,
21 such State shall submit to the Secretary, and
22 make publicly available on the appropriate
23 State website, a report on how the State is im-
24 plementing guidance issued under subsection

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

3 “(h) RULE OF CONSTRUCTION.—Nothing in this sec-
4 tion may be construed—

5 “(1) to require a child with medically complex
6 conditions to enroll in a health home under this sec-
7 tion;

8 “(2) to limit the choice of a child with medically
9 complex conditions in selecting a designated pro-
10 vider, team of health care professionals operating
11 with such a provider, or health team that meets the
12 health home qualification standards established
13 under subsection (b) as the child’s health home; or

14 “(3) to reduce or otherwise modify—

15 “(A) the entitlement of children with medi-
16 cally complex conditions to early and periodic
17 screening, diagnostic, and treatment services
18 (as defined in section 1905(r)); or

19 “(B) the informing, providing, arranging,
20 and reporting requirements of a State under
21 section 1902(a)(43).

22 “(i) DEFINITIONS.—In this section:

23 “(1) CHILD WITH MEDICALLY COMPLEX CONDI-
24 TIONS.—

1 “(A) IN GENERAL.—Subject to subpara-
2 graph (B), the term ‘child with medically com-
3 plex conditions’ means an individual under 21
4 years of age who—

5 “(i) is eligible for medical assistance
6 under the State plan (or under a waiver of
7 such plan); and

8 “(ii) has at least—

9 “(I) one or more chronic condi-
10 tions that cumulatively affect three or
11 more organ systems and severely re-
12 duces cognitive or physical functioning
13 (such as the ability to eat, drink, or
14 breathe independently) and that also
15 requires the use of medication, dura-
16 ble medical equipment, therapy, sur-
17 gery, or other treatments; or

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

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

1 or severity of chronic, life threatening illnesses,
2 disabilities, rare diseases or mental health con-
3 ditions for purposes of determining eligibility
4 for receipt of health home services under this
5 section.

6 “(2) CHRONIC CONDITION.—The term ‘chronic
7 condition’ means a serious, long-term physical, men-
8 tal, or developmental disability or disease, including
9 the following:

10 “(A) Cerebral palsy.

11 “(B) Cystic fibrosis.

12 “(C) HIV/AIDS.

13 “(D) Blood diseases, such as anemia or
14 sickle cell disease.

15 “(E) Muscular dystrophy.

16 “(F) Spina bifida.

17 “(G) Epilepsy.

18 “(H) Severe autism spectrum disorder.

19 “(I) Serious emotional disturbance or seri-
20 ous mental health illness.

21 “(3) HEALTH HOME.—The term ‘health home’
22 means a designated provider (including a provider
23 that operates in coordination with a team of health
24 care professionals) or a health team selected by a

1 child with medically complex conditions (or the fam-
2 ily of such child) to provide health home services.

3 “(4) HEALTH HOME SERVICES.—

4 “(A) IN GENERAL.—The term ‘health
5 home services’ means comprehensive and timely
6 high-quality services described in subparagraph
7 (B) that are provided by a designated provider,
8 a team of health care professionals operating
9 with such a provider, or a health team.

10 “(B) SERVICES DESCRIBED.—The services
11 described in this subparagraph shall include—

12 “(i) comprehensive care management;

13 “(ii) care coordination, health pro-
14 motion, and providing access to the full
15 range of pediatric specialty and sub-
16 specialty medical services, including serv-
17 ices from out-of-State providers, as medi-
18 cally necessary;

19 “(iii) comprehensive transitional care,
20 including appropriate follow-up, from inpa-
21 tient to other settings;

22 “(iv) patient and family support (in-
23 cluding authorized representatives);

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

1 “(vi) use of health information tech-
2 nology to link services, as feasible and ap-
3 propriate.

4 “(5) DESIGNATED PROVIDER.—The term ‘des-
5 ignated provider’ means a physician (including a pe-
6 diatrician or a pediatric specialty or subspecialty
7 provider), children’s hospital, clinical practice or
8 clinical group practice, prepaid inpatient health plan
9 or prepaid ambulatory health plan (as defined by the
10 Secretary), rural clinic, community health center,
11 community mental health center, home health agen-
12 cy, or any other entity or provider that is deter-
13 mined by the State and approved by the Secretary
14 to be qualified to be a health home for children with
15 medically complex conditions on the basis of docu-
16 mentation evidencing that the entity has the sys-
17 tems, expertise, and infrastructure in place to pro-
18 vide health home services. Such term may include
19 providers who are employed by, or affiliated with, a
20 children’s hospital.

21 “(6) TEAM OF HEALTH CARE PROFES-
22 SIONALS.—The term ‘team of health care profes-
23 sionals’ means a team of health care professionals
24 (as described in the State plan amendment under
25 this section) that may—

1 “(A) include—

2 “(i) physicians and other profes-
3 sionals, such as pediatricians or pediatric
4 specialty or subspecialty providers, nurse
5 care coordinators, dietitians, nutritionists,
6 social workers, behavioral health profes-
7 sionals, physical therapists, occupational
8 therapists, speech pathologists, nurses, in-
9 dividuals with experience in medical sup-
10 portive technologies, or any professionals
11 determined to be appropriate by the State
12 and approved by the Secretary;

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

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

18 “(B) be freestanding, virtual, or based at
19 a children’s hospital, hospital, community
20 health center, community mental health center,
21 rural clinic, clinical practice or clinical group
22 practice, academic health center, or any entity
23 determined to be appropriate by the State and
24 approved by the Secretary.

1 “(7) HEALTH TEAM.—The term ‘health team’
2 has the meaning given such term for purposes of
3 section 3502 of Public Law 111–148.”.

○